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READERS'
POLL
INSIDE

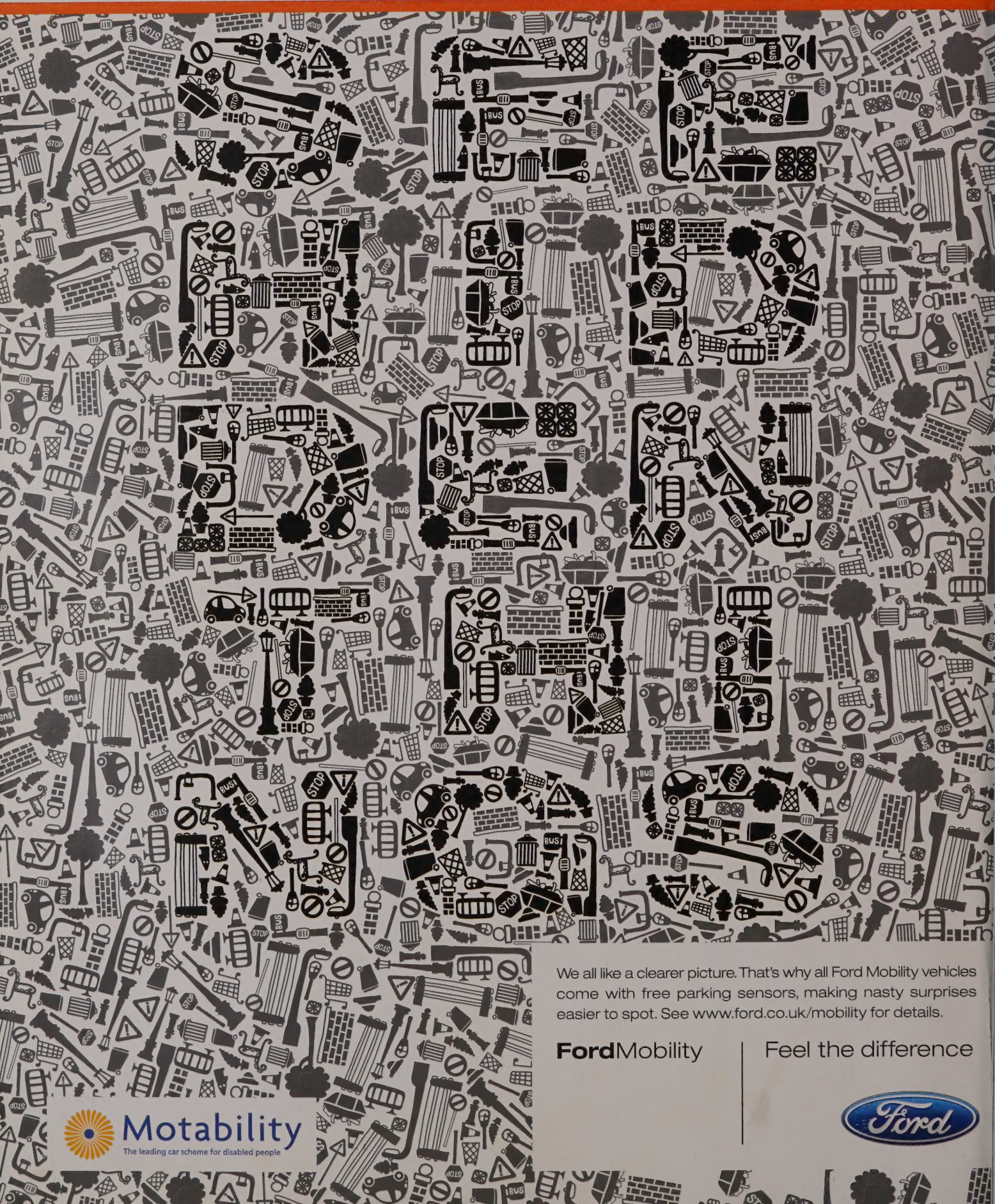
Who'll be your Disabled Legend?

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April 2010
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editorial

The stuff of legends

The noun “icon” and its associated adjective are words which are overused. This usage is causing their meaning to be eroded so that they become all-purpose descriptions of anything or anyone who is anything from important to unique or brilliant. The other day, for instance I heard someone label cricket commentator Brian Johnston “an iconic voice”. What’s that supposed to mean?

So we’ve decided to use a different term in our readers’ poll in this issue and on the website. We’re asking you to name *Disability Now*’s Disabled Legend.

When you look at the list of 50 people on page 22 it brings home the breadth of fields in which disabled people have found success or deserve recognition. But what’s perhaps more significant is the way in which what many of them did was shaped by what they are or were.

Spike Milligan practically re-invented comedy in the 1950s. But arguably he would not have been the creative force he was without his mental health condition which in part gave him his perspective on the world.

As was said in the previous issue of *Disability Now*, Ian Dury’s whole approach to

music, lyrics, performance, indeed life, was shaped by his experience as a disabled person.

Beethoven seems to have been hugely motivated by the very fact of his deafness, spurred on to greater and more profound musical achievements.

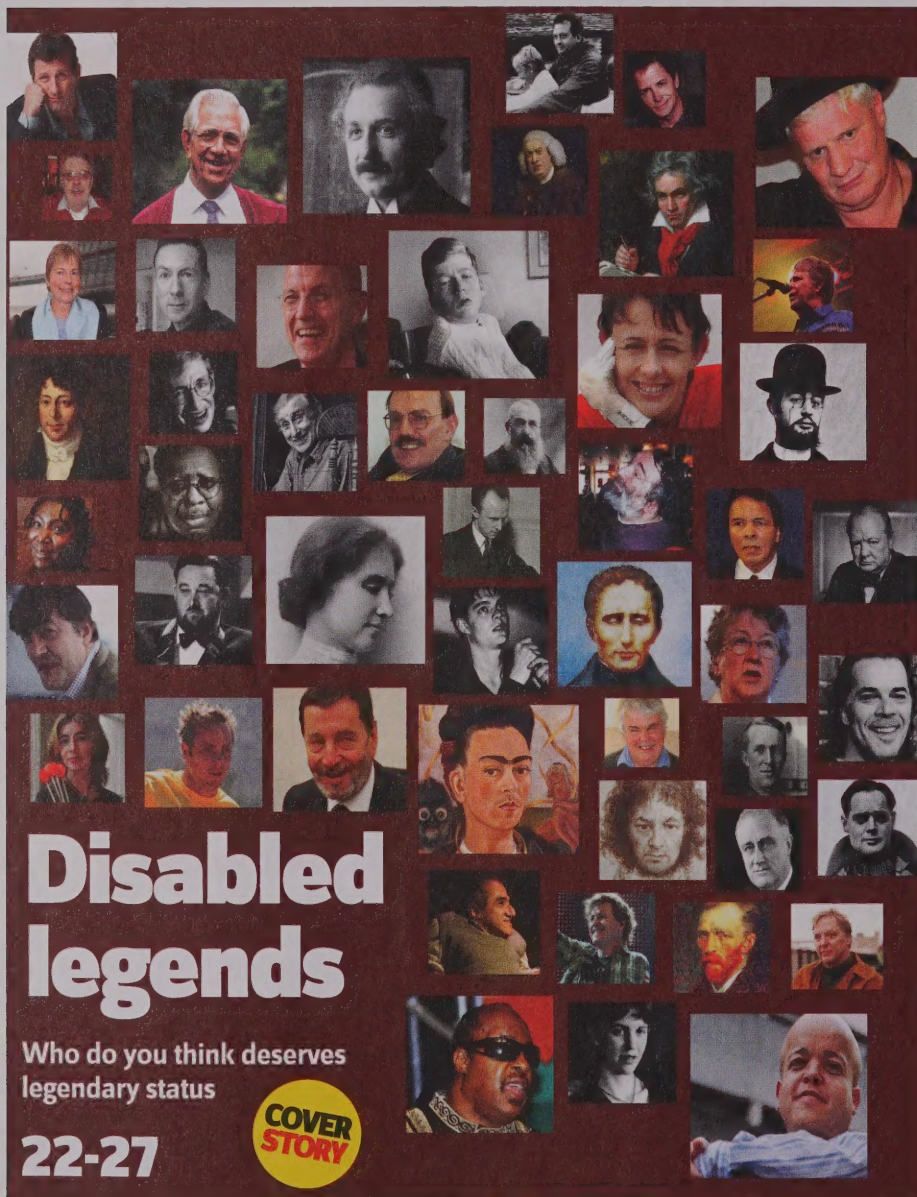
“When you look at the list of 50 people on page 22 it brings home the breadth of fields in which disabled people have found success or deserve recognition”

In a similar way, it was who they were, and society’s attitudes towards them that drove the activism and campaigning of people like Baroness Campbell, Professor Mike Oliver, Colin Barnes and Rachel Hurst.

To put it more clearly, all those on the list are admirable, not simply because they have impairments and have in some way overcome them, but because what they are as disabled people has contributed to what they became and achieved as human beings.

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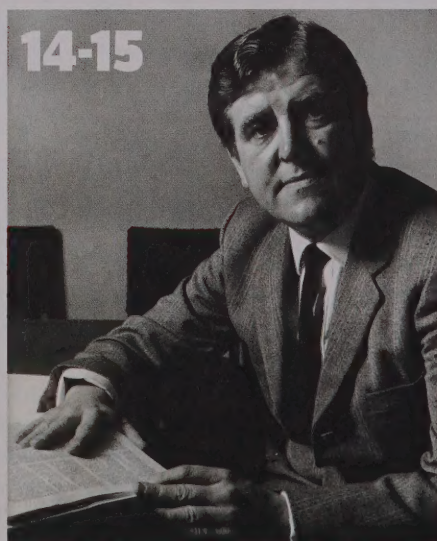
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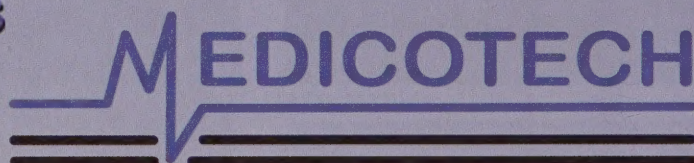
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newsview

Starmer denies opening door to mercy killing

Ian Macrae

The much anticipated guidelines on assisted suicide, produced by Keir Starmer, the Director of Public Prosecutions (DPP), in response to a request from the law lords, found a more than half-hearted welcome from a surprising quarter.

Baroness Campbell of Surbiton was "personally quite relieved" to see that disability and long-term illness were not included (as they were in the interim guidelines) as possible grounds for not prosecuting someone who had helped someone else to die.

She told *Disability Now*, "The fact they've taken out disability and long-term illness as mitigating factors is a huge victory. And we mustn't forget or underestimate the fact that this was really and truly down to the representations of disabled people."

Starmer himself supports that view.

"The argument that by including disability, you sent messages to people about the value of lives was made by a number of individuals in a number of different ways and the more I heard it the more important I thought it was."

Such accord isn't evident

everywhere. Disabled people and their allies continue to argue that the existence of the guidelines in itself waters down the law as it stands.

Under the 1961 Suicide Act, anyone convicted of helping another person to kill themselves is liable to a maximum sentence of 14 years' imprisonment. Some argue that this provision gives adequate and proper protection and penalty.

But Starmer contends that this argument oversimplifies the position.

"The law is clear in the sense that it criminalises assisted suicide. But it's equally clear in the express requirement that the DPP should consent to any prosecution. So the model set up in the 1961 Act was a prohibition on assisted suicide, but coupled with a

“The idea that without the guidelines people wouldn't be having that discussion is a little fanciful”

discretion as to whether to prosecute or not."

Therefore, in asking for clarity on whether or not her husband would be likely to face prosecution for helping her to die, Debbie



Keir Starmer: "I don't express a view on mercy killing."

Purdy was in effect seeking clarification on the grounds on which discretion would be exercised, hence the new guidelines.

So, Starmer says, "The law without the policy is clear only to the extent of saying that you've got to exercise discretion. I'm not sure that gets you very far."

But fears remain among disabled campaigners and are shared by religious leaders like Archbishop John Sentamu. They argue that allowing for weakening of the law in one area risks

opening up the much wider and more frightening prospect of allowing mercy killing or euthanasia.

Starmer acknowledges that these are on the public agenda, if not his own.

"There's a discussion that a number of people want to have on mercy killing. I don't express a view or participate in that discussion. But the idea that without the guidelines people wouldn't be having that discussion is a little fanciful. It's a discussion which people will have, guidelines or not."

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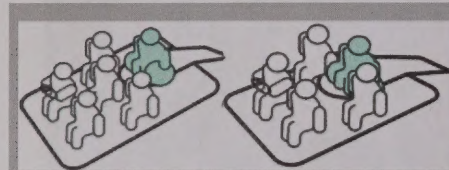
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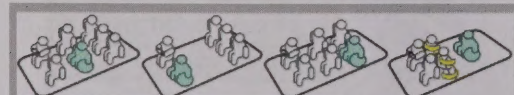
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Charity axes disabled support staff

Sunil Peck

Charity and service provider Leonard Cheshire Disability (LCD) looks to have pulled back on two of its major commitments to disabled people.

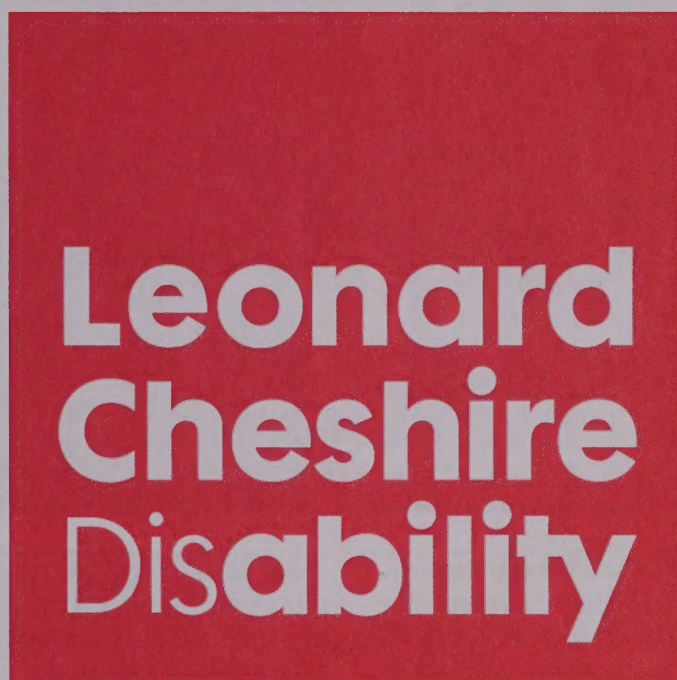
Users of LCD services and those employed to support them have been left "angry and "betrayed" by the charity's plans to close its service user support team in the face of a commitment made last year to involve service users when deciding how it spends its income.

But the service users' network association (SUNA) says that it has not been consulted about the proposals to close the support team.

The support team has 30 staff who are employed by LCD, of whom 26 are disabled. *Disability Now* understands that all the posts in the support team are at risk and that only five new posts, which would not be reserved for disabled people, would be created.

These cuts come at a time when disability charities are trying to lead by example by increasing the number of disabled staff they employ.

One service user said that LCD's plans reflected a lack of awareness of the work



Leonard Cheshire Disability: The website advertises "Make a positive difference to someone's life right now" and "We campaign for change and provide innovative services that give disabled people the opportunity to live life their way."

the support team had done to transform disabled people's lives.

The source added that LCD had benefitted financially from its support team because people had been attracted to choose and pay for LCD services because of the added level of support it provided.

But the source added: "Because there will be a lack of support from the service user support team, the service users network will fall apart in two to three

years, because there will be nobody to train and bring any new people through."

The service users support team provides one-to-one peer support to develop users' confidence and skills, in addition to supporting users with learning difficulties and communication impairments to access LCD's services and external services like counselling and mentoring for people who wish to live independently.

Another SUNA source added: "If you wanted to

put a compliment or complaint in and didn't know how to do so, the support team would be there to act as your advocate. Users will lose their voice without the service user support team."

An LCD spokesman told *Disability Now* that the charity's proposals had been prompted by "financial pressures".

"Voluntary income from individuals and business has fallen during the recession and there is no sign yet that charitable giving is set to improve."

A support team source said the team accepted that cuts had been inevitable, but there was nevertheless a mood of resentment and anger at the way LCD was handling the situation.

"The organisation had a strategic review last year which involved numerous people being made redundant. Our team was kept out of that process and were promised that there would be a full and in-depth six-month review of the team's work. That meant that all the new jobs available as part of the strategy were only open to people at risk of redundancy. Now we are at risk there are very few jobs open to us."

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Pilkington, police under IPCC scrutiny

Paul Carter

The Independent Police Complaints Commission (IPCC) has announced that ten police officers are under investigation as part of a "complex" and "ongoing" inquiry into the handling of the case of Fiona Pilkington.

Mrs Pilkington killed herself and her disabled daughter Francecca Hardwick in October 2007 by setting alight the family car following years of abuse and harassment from a gang of local youths in Barwell, Leicestershire.

The inquest into their deaths revealed that Mrs Pilkington made 33 calls to police over a ten year period, but received only eight visits from officers.

A statement from the

IPCC said the Commission had gathered a variety of material from the police and local authority, who had all "co-operated fully".

The statement read: "We have now served advisory notices on a total of ten Leicestershire police officers and this situation is being kept under review. Such notices are not judgemental in any way, but are required under police misconduct regulations, and served on officers to advise them that their conduct is under investigation.

"This complex inquiry is going back over police contact with Fiona Pilkington, her daughter and neighbours over a period of several years. We are assessing information from family members, neighbours,

the authorities involved, records of police contact, and the accounts of relevant police officers themselves."

It added: "The extensive nature of the investigation means there is still substantial further work to do, and enquiries to be made by the IPCC. We are progressing this rigorous investigation as swiftly as possible and will make our findings public in due course."

The news comes shortly after a series of "report cards" from HMIC, the independent police inspectorate for forces in England, Wales and Northern Ireland, revealed that while 22 per cent of repeat victims of anti-social behaviour categorise themselves as disabled, more than half of the 43 forces do not have systems capable of

identifying repeat victims, meaning often officers are unaware of the previous history.

The Chief Inspector of Constabulary, Denis O'Connor said that this recording of information was "inadequate".

An HMIC spokesman told *Disability Now* that part of the problem for police forces is that the distinctions between anti-social behaviour and crime are often blurred, and the report claims that members of the public on the receiving end of anti-social behaviour "find it hard to distinguish it from crime".

However, this is unlikely to sit well with anti-disability hate crime campaigners, who have lobbied continually for anti-social behaviour and bullying to be taken more seriously by the authorities and, where appropriate, treated as hate crimes.

On the day that the report cards were published, details emerged of the death of another person with learning difficulties.

David Askew, from Hattersley in Greater Manchester, collapsed and died at his home. Neighbours alleged he had been harassed and abused for many years. As *Disability Now* went to press, Greater Manchester Police said two men had been arrested in connection with the inquiry into Mr Askew's death.



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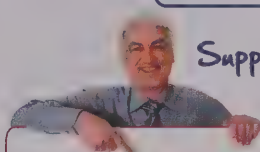
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ruthpatrick

Britain's next top model



For years, disability has been defined in medical terms. More recently, campaigners have put the emphasis on how society fails disabled people. **Ruth Patrick** argues that it's now time for an entirely new way of thinking

I recently spent several long nights marking a set of first year undergraduate exams.

One of the essay questions asked the students to think about the impact of the social model of disability on British policy making. Not all the students grasped the essence of the social model stance: that disability is the physical and attitudinal barriers which society places on those living with impairments. This challenges the traditional medical model of disability which equates disability with impairment and depicts it very much as a "personal tragedy".

If I had been sitting the exam myself, I would have started by trying to list all the positive things which have come about, at least in part, due to the social model. However, an important caveat would first be required. It is not so much the social model construct which has effected great change but the continued commitment of those in the disability movement, who



JAMIE TROUNCE

have loudly and repeatedly demanded better rights and recognition for disabled people. The social model's unique power has been to provide an overarching framework for the disability movement's efforts to effect emancipatory change.

Key moments include the passage of the Disability Discrimination Act; the United Nations Convention on the Rights of Persons with Disabilities; and New Labour's stated objective that by 2025 full equality will be realised for all disabled people. Furthermore, the rise in direct payments, the shift towards inclusive education, and increasing support for independent living all suggest a social

model influence.

However, it is not a flawless model and has been particularly troublesome in tending to encourage a complete focus on societal barriers and a consequent neglect of impairments. The individual experience of living with and coping with impairment(s) is an important one which helps shape individuals' identities.

Talking about and sharing the experiences of impairment can also have emancipatory potential by breaking down the barriers of fear and stigma which are

so often associated with disability. This is particularly true of mental health challenges which, when hidden and only talked about in hushed whispers, can all too easily become caricatured and frightening. Early social model campaigners were often opposed to incorporating impairment, for fear of diluting the social model's potential impact. However, it is now time to look to the impairment dimension and consider how this too can be championed and incorporated into a liberating discourse of disability.

Thus, my exam answer would conclude. The time to talk about impairment has come, but this should be married to a continued effort to articulate the clarion call of the social model: that it is society that needs to change rather than individual disabled people. This message has started to seep in, but many in the media, in parliament, and much of the wider public have yet to grasp the point.

→ Have your say

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- phone us 020 7619 7323

politics

Issues like social care and independent living are high on the political agenda now, but just over 40 years ago before the Chronically Sick and Disabled Persons Act was passed, disabled people were all but invisible to politicians.

Lord (Jack) Ashley of Stoke, who was an MP at the time, says that it is difficult to convey the extent of the discrimination faced by disabled people before 1970.

"In the 1950s and 1960s, we had no interest in parliament at all in disability. The two words were neglect and discrimination and especially in such fields as employment, qualifications and general poverty. Disabled people were out of the picture and this meant that they were out of mind and took no part in the discussions about future policy on disability or indeed any policy."

The fact that there has been a shift towards inclusion is largely down to the efforts and passion of Lord [Alf] Morris of Manchester who introduced the original bill.

But why did Alf Morris, a non-disabled Labour MP, now a peer, take up the cause of disabled people in the first place?

"My earliest memories are of my father waiting to die.

FORTY YEARS ON

The Chronically Sick and Disabled Persons Act was the first piece of disability legislation in the world. Looking back to its inception and parliamentary passage, **Sunil Peck** discovers that it was helped by a large piece of luck and hindered by ministerial hostility and political events



Lord Morris was made a Fellow of the Royal College of Physicians last year and the photo shows the President of the College, Professor Ian Gilmore, presenting the official scroll to him. This took place at a ceremony there on 6 July 2009.

He was very badly gassed in the First World War and his lungs were cut to pieces. He lost a leg and an eye in the war too. My wife's father was also badly gassed and her mother was in a wheelchair. We had a shared indignity because I used to

have to lift her out of the wheelchair into the bath."

But despite his conviction that disabled people should be able to lead more dignified lives, it was only a stroke of good fortune that enabled him to pursue the bill.

"I had no expectation of being given the opportunity to legislate in the policy area of my choice. It was the purist accident and had nothing to do with the quality of my ideas; it was the quality of my luck that brought me first place in

the private members ballot in 1969. The odds against winning were about six hundred to one."

Having won the ballot, he had the task of drafting a piece of legislation that stood a decent chance of becoming law.

"I trawled all the organisations of disability and only one came forward with any idea of a proposition that I could make in the bill. It came from Mary Appleby, the general secretary of the charity now known as Mind. She said that we needed to know for the first time ever how many disabled people there are in Britain. That became clause one of my legislation."

The Chronically Sick and Disabled Persons Act, the first piece of disability-related legislation in the world, also recognised disabled people's right to access the built environment and public transport and gave practical help at home including the installation of telephones. It also brought legal recognition of autism and dyslexia.

And all this in the face of hostility from key figures in the Labour party including Dick Crossman the Minister for Social Services whose advice Morris sought when he was drafting the bill.

"He got very angry with me. His attitude was 'who do you think you are to



Alf Morris, 40 years ago

come here with all your five years of parliamentary experience lecturing me on social priorities'? He said that the most helpful thing I could do would be to rip the bill up."

In fact, the bill did come close to failing. It made it through the Commons and was making its way through the Lords when Harold Wilson announced the date of the 1970 general election.

"That meant that the bill was dead in the water," says Lord Morris.

"When a general election is announced, the leaders of all the parties meet and decide which bills can be cleared. You've only got about five days so very few pieces of legislation will go through. Harold Evans, the

editor of the Sunday Times, wrote a leading article and said that the only bill worth saving from the ragbag of legislation was the Chronically Sick and Disabled Persons Bill."

“What it did was bring disabled people out of the closet. It was the first time MPs would go on television discussing disability”

It's a salutary note that, despite the Act, we still don't know the exact number of disabled people in Britain. The intentions of Morris and the bill he'd championed, such as

disabled people's right to an accessible built environment and social care were also undermined by unfavourable legal judgements which tested the Act soon after it was passed.

But Bert Massie, now Sir Bert, who travelled from Liverpool to London to lobby his MP to back the campaign for disability benefits as well as the bill, says that the Act left an important legacy.

"What it did was bring disabled people out of the closet. It was the first time MPs would go on television discussing disability. The Act really was a breakthrough in that disabled people were suddenly on the political agenda."

But Sir Bert says the Act remains a beginning. He emphasises that disabled people will have to carry on the campaign which the Act began if full equality is to be a reality in another 40 years.

Lord Ashley says that the Act has been a "starting pistol" for subsequent legislation aimed at bringing about greater equality such as the Disability Discrimination Act.

But he agrees with Sir Bert.

"There's always a further step. These are important steps on the way but they are not the ultimate. We'll be demanding more and more and more."

mediawatch

In the past year, three big TV soap operas have introduced disabled actors into their cast. Now the final big player is following suit, as wheelchair-user Cherylee Houston moves onto *Coronation Street* in April. But, like those before her, she seems to have personal problems. **Cathy Reay** asks what the big deal is

It's quite astonishing to think that, less than 18 months ago, a disabled actor had never been cast as a regular character in a British soap opera.

Now, they're everywhere, from wheelchair users David Proud in *EastEnders* and Kelly-Marie Stewart in *Hollyoaks* to blind actress Kitty McGeever in *Emmerdale* and now Cherylee Houston in *Coronation Street*.

It's unarguably fantastic that programme producers are responding to the fact that there are hugely talented disabled actors out there and are pushing them into the limelight.

But it's also evident that producers have responded to concerns within the disabled community by not tiptoeing round disability and ensuring their disabled characters don't elicit pity. They've done this by giving these characters a range of personality traits, including some that are pretty nasty.

Their motivation is understandable. Disabled people aren't angelic just because they're disabled.

But suppose the balance has swung too far the other way and they're sending out



the message that all disabled characters are also bad or neurotic, and that their flaws are linked in some way to their disability?

Blind actress Kitty McGeever (above) joined *Emmerdale* early last year as lively Lizzie Lakely, a feisty character with a penchant for petty thievery. Mouthy and ballsy, she isn't above using the fact that she can't see to get what she wants.

But Lizzie's anger isn't the product of her disability. "Her edge is a kick against the way disability has been portrayed on TV for years," says Kitty. "It can be soul-destroying to watch disabled people crying and moaning on-screen and saying 'Get me out of my chair.'"

Has Lizzie's character development been tied by

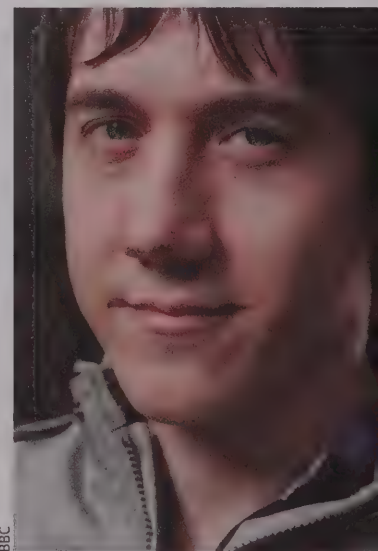
No soft soap on disability

the scriptwriters to her disability? "I don't think the character Lizzie has a chip on her shoulder [about being disabled]," says Kitty. "As much as it was made clear she's hard, it's because she was left without parents, not because she's blind. But tempered with that, she's also warm and humorous. People tend to think 'You can't help but like this girl.'"

David Proud (right) joined the cast of *EastEnders* last summer as Manda's son Adam Best, a character the BBC described as "snobbish" and "self-centred". Through his conniving ways, Adam comes across as malicious, selfish and unkind, though David is quick to deny his script-editor has landed him with a disability-related evil. "At some point we'll get to see what makes Adam tick. [At the moment] it's not completely obvious [but] there are other issues he has that are nothing to do with his wheelchair," he says.

David admits that since

he first appeared on screen in November 2009, more and more people have come up to him on the street to tell him how irritating his character is, though warmly.



"Most memorable characters in a soap are flawed; they aren't straight-laced," he says. "Nice characters don't have the same impact. Adam is multi-dimensional; he needs the love of a good woman to sort him out!"

It was Kelly-Marie Stewart (right) who was first in the door when she snagged the role of Hayley Ramsey in teen soap *Hollyoaks* last December. Since joining the show, her character has made a fair few enemies, though she seems the least troubled of the three. In the case of Hayley's pregnancy, that was written into the script



LIME PICTURES

after Kelly-Marie revealed her own real-life pregnancy. *Hollyoaks* creators chose to treat her just like any other member of the cast.

The usual tendency in soaps is for producers to play off virtue against vice. Since viewers cut disabled characters more slack than able-bodied characters, it's natural that script-editors

will set their disabled characters up to perform against expectation. The dangers come when performing against expectation becomes a habit. When ITV's press release came out, it announced Cherylee Houston's character Izzy as "fiery" and "feisty", a personality not to be messed with, a personality troubled by her past. Lizzie Lakely, Adam Best and Hayley Ramsey had all been described in similar terms.

So maybe the tide has gone too far. There now seems to be a convention

by which programmers routinely make disabled characters vengeful and personality-driven. Is it too much to ask for a disabled person to play the good guy for once?

• **Cherylee Houston will first appear as Izzy (sur - name tba) in Coronation Street on 16 April.**

• • **What do you think of David, Kitty and Kelly-Marie's characters? Do you think they paint a positive or negative image of disability? Visit disabilitynow.org.uk to leave your comments.**

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disabilityrights

Missing links in autism strategy

Adult autism strategy consultation

Your chance to shape the future

Return to Department of Health consultation home page



The Government's new strategy for adults in England with autism offers important recommendations that, properly implemented, will make a real difference, says **Anya Ustaszewski**. But what about equality?

On 3 March, the Government announced a landmark strategy to transform adult autism support. I welcome this but I don't welcome various issues relating to the development of the strategy and the thinking behind the draft report.

First, there was a lack of inclusion of autistics. A few autistic individuals were brought into the External Reference Group, but only after a last-minute meeting with the London Autistic Rights Movement and the National Autistic Society.

In addition, meetings took place in conference rooms with glaring lighting – an inappropriate setting for people with sensory issues.

And then the timescale for producing the draft report was shortened from two months to only three weeks, despite the Department of Health's awareness

that sudden change is very stressful for autistics.

Second, there's a short-sightedness about the strategy. It cites existing legislation that should apply to autistics, for example, and adds that its approach is "to identify how to make existing policies work better," but fails to grasp that if existing legislation is proving to be of little help, we need better laws and harsher penalties for disregarding it.

The strategy goes on to give examples of how existing policies could be better used within public services. It overlooks the fact that most of us have lives outside the public services.

There are some promising recommendations, such as training for all frontline staff and more consistent pathways to diagnosis, but from an autistic rights point of view there are many

other areas of concern.

Although there are references to including autistics in the delivery of training and commissioning of services, these are very vague. The strategy is clear about recommending the creation of various boards and committees but fails to specify that these boards must include autistics.

The strategy also seems to lose sight of the social model of disability. It recommends that "travel training is made available" to autistics but misses the point that public transport is often hopelessly inaccessible.

There is a strong emphasis on helping autistics find and hold onto employment. What does concern me is that the strategy doesn't appear to acknowledge that work may not be a possibility for everyone. It's important that people aren't judged purely in

terms of their economic productivity.

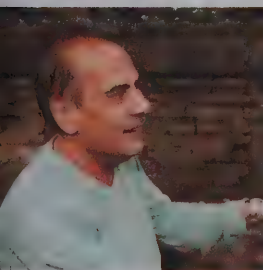
The strategy asserts that increasing awareness through employers "will also begin the process of raising public awareness ... reducing stereotypes and misconceptions". I can't help thinking this is a little naïve. Just because an autistic has a job, it doesn't follow that if he or she stims [engages in self-stimulatory or repetitive behaviours] in public, people won't stare and mock. It doesn't also mean that the stereotyping that occurs in the media will automatically cease.

The recommendations in the strategy could help autistics gain access to better support and be treated more equally, but I'm disappointed that it doesn't go far enough to ensure genuine inclusion of autistics in influencing and shaping policy that directly affects us.

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worldview

Part of the Union

The European Union has grown in size and now encompasses some 65 million disabled people living in almost 30 different countries. **Aurélien Daydé** of the European Disability Forum looks at developments in European campaigning

There are more than 65 million in Europe with a disability of some kind, but many people with disabilities are still invisible and have to put up with discrimination, social exclusion, isolation and, too often, poverty.

It's because of this that, 13 years ago, activists with disabilities or with disabled children joined forces to create the European Disability Forum (EDF), with the aim of influencing European institutions and decision-making.

For the last decade EDF has helped develop both the United Nations Convention on the Rights of Persons with Disabilities and the Council of Europe Action Plan. We have also worked closely with numerous European bodies including industry and consumer organisations.

In spite of these efforts, there is currently no long-term EU agenda on disability with a clear joint commitment from the institutions and member states. Each state, of which there are 27, is developing its own national disability action plan, and each one is different. To free Europe of its barriers, we need to co-ordinate the European Action Plan with the various national plans, ensuring that clear and measurable objectives are

linked to the EU strategy for growth and jobs.

Improving access to transport and information technology will help break down European barriers. We also need to encourage an inclusive education system that promotes quality services and increases social, economic and cultural access.

Most of the important day-to-day issues in Europe are now governed by the complex decision-making processes of its main bodies: the Commission, the Parliament and the meetings of member states.

The Commission is made up of different "Directorates General" – ministry-like bodies that deal with most of the details of European legislation. Within the Directorate for Employment and Social Affairs, EDF is working with a unit that specialises in integrating disabled people.

Members of the European Parliament (MEPs) do much of their work in committee, some of them, like the employment and social affairs committee, with hundreds of MEP members. In addition to these formal or statutory groups, there are informal activist groups such as the Disability Intergroup (DI). The DI is made up of MEPs from all nationalities and most political groups who want

to promote disability policy across Europe and nationally.

The DI, established in 1980, is one of the older intergroups. It is currently made up of about 100 MEPs. In December 2009, it elected as its president Ádám Kósa, a Hungarian politician and the first deaf person to become an MEP.

At a cocktail party held by the DI, the Vice-President of the European Parliament, Pál Schmitt, welcomed his Hungarian colleague and expressed his support for the disability movement. Yannis Vardakastanis, President of EDF, added that this was a historic day for Europe's 65 million people with disabilities and that for the first time in the DI's history, its motto, "Nothing about us without us" was becoming a reality.

In replying, Ádám Kósa said: "I dream that disabled people will finally decide for themselves. Full ratification by the UN Convention on the Rights of Persons with Disabilities and the adoption of the Disability Pact by the EU member states are the necessary steps to achieve this dream."

The active involvement of disabled persons in future developments is essential. If full participation becomes a reality, the EDF's Disability Pact will contribute to a truly inclusive society.

It's time to choose! Who is your **DISABLED LEGEND?**

Who's the person who's done most as a disabled thinker, performer, activist, entertainer or sports star who you think deserves the status of **LEGEND**? Which of our 50 contenders, historical and contemporary, has done most to shape the way disabled people are viewed and treated? Which of them has done most to raise the profile or improve the standing of our community? **YOU TELL US!**

Each of *Disability Now*'s reporters and regular writers has put together a list of the people they believe are Disabled Legends.

We've then put all the names together to produce what is, in anyone's book, an impressive list.

From Stephen Hawking to Stevie Wonder, Tanni Grey-Thompson to Henri de Toulouse-Lautrec, Beethoven to Baroness Campbell, Spike Milligan to Bert Massie.

Their names have come from across the centuries and from a wide range of

activities from politics to pop, painting and poetry, from activism to acting.

But they have one thing in common. And that's not just that they're disabled, but that what they are has informed what they've done and shaped the way in which they've been viewed by society.

NOW IT'S YOUR TURN!

We're asking you to vote for one of our 50 likely legends.

Which one of the people on page 23 and on our website would you say has done most to further the cause, raise the profile of or change attitudes towards disabled people? To start you thinking, each of our writers has chosen one of their nominees they want to champion. Read their choices online or on the following pages.

MAKE YOUR VOTE COUNT

Using the form which came as a flyer in this issue, vote for the person you think most deserves to be a Disabled Legend.

Alternatively, go to disabilitynow.org.uk and cast your vote there.

Address for votes by post is: FREEPOST, Disability Now (Envelope but no stamp required)

THE CONTENDERS

Who gets your vote?



Rick Allen – Rock drummer with Def Leppard



Muhammad Ali – All-time boxing great



Lord Jack Ashley – Veteran politician and stalwart campaigner



Douglas Bader – Wartime air ace and POW escapee



Ludwig van Beethoven – Composer



Colin Barnes – Academic and disability rights champion



Jean-Dominique Bauby – Novelist, author of *The Diving Bell and the Butterfly*



David Blunkett – Former Labour Cabinet Minister



Louis Braille – Inventor of literacy system for visually impaired people



Baroness Jane Campbell – Campaigner, activist and equality champion



Patricia Chambers – Mental health campaigner



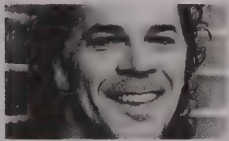
Sir Winston Churchill – Wartime Prime Minister



Ian Curtis – Innovative post-punk musician



Chris Davies – Writer, broadcaster, campaigner



Ian Dury – Musician, hit-maker



Albert Einstein – Pioneering physicist



Michael Flanders – Humorist, performer, raconteur



Michael J Fox – Film actor, campaigner



Stephen Fry – Actor, mental health champion



Frank Gardner – Security correspondent and specialist



Evelyn Glennie – Percussionist, music champion



Goya – Painter



Tanni Grey-Thompson – Athlete, sport ambassador, campaigner



Joseph Grimaldi – Clown



Stephen Hawking – Physicist, science ambassador, Simpsons guest star



Adam Hills – Comedian



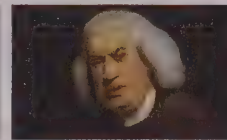
John Hockenberry – Journalist, TV and radio presenter



Alan Holdsworth (aka Johnny Crescendo) – Activist, performer



Rachel Hurst – Veteran activist, rights champion and campaigner



Dr Samuel Johnson – Lexicographer and raconteur



Frida Kahlo – Artist



Helen Keller – Campaigner, disability ambassador



Henri de Toulouse-Lautrec – Painter, observer of life



T E Lawrence – Soldier, writer



Sir Bert Massie – Activist, rights champion, former head of RADAR



Curtis Mayfield – Soul singer



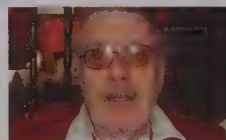
Spike Milligan – Innovative comic performer and writer



Claude Monet – Impressionist painter



Christopher (Christy) Nolan – Distinctive author



Mike Oliver – Academic and activist



Oscar Pistorius – World-class athlete



Sylvia Plath – Poet



Franklin D Roosevelt – Former American President



Nabil Shaban – Actor, writer, activist



Tom Shakespeare – Writer, campaigner, academic



Vincent Van Gogh – Painter



Peter White – Broadcaster, Disability Now columnist



Brian Wilson – Musician, mental health survivor

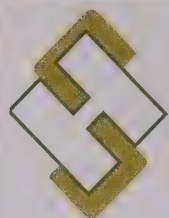


Sir John Wilson – Founder, Sightsavers International



Stevie Wonder – Musician, blind ambassador





Sussex Health Care



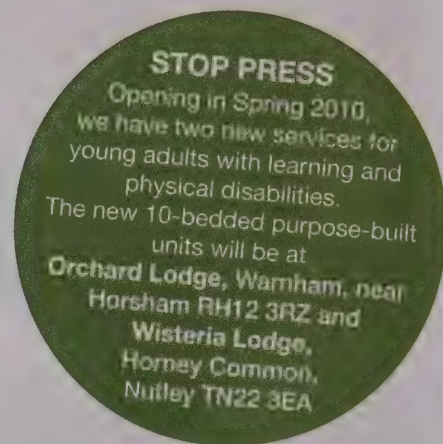
Sussex Health Care is an award winning group of care homes that were founded in 1985. Sussex Health Care now operates 16 care homes, predominantly in the West Sussex area, providing nearly 550 beds, incorporating specialist care provision including care for older people.

Orchard Lodge, Dorking Road, Warnham, West Sussex RH12 3RZ

Orchard Lodge, just outside Horsham, West Sussex, provides care for adults with learning and physical disabilities. This specialist care home with nursing combines the latest technological facilities with a safe and comfortable environment. Activity rooms are available to all service users along with sensory and physiotherapy rooms. Hydrotherapy services are available in the swimming pool and spa with multi-purpose rooms for structured activities.

Wisteria Lodge, Horney Common, Nutley, East Sussex TN22 3EA

Wisteria Lodge in Nutley, East Sussex, caters for young people with physical and learning disabilities. The home offers superb purpose-built facilities with track hoisting throughout. Each single room provides en suite facilities. A spa pool is available to all service users along with sensory and physiotherapy rooms.



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- BEECH LODGE (Physical & Learning Disabilities) Horsham 01403 791725
- HORNCastle CARE CENTRE (Acquired Brain Injury & Neurological Conditions) East Grinstead 01342 813910
- KINGSMEAD LODGE (Physical & Learning Disabilities) Horsham 01403 211790
- NORFOLK LODGE (Learning Disabilities) Horsham 01403 218876
- ORCHARD LODGE (Physical & Learning Disabilities) Warnham 01403 242278
- RAPKYNs CARE HOME (Adult Care & Neurological Conditions) Horsham 01403 265096
- RAPKYNs CARE CENTRE (Physical & Learning Disabilities), Horsham 01403 276756
- WHITE LODGE (Learning Disabilities) Purley, Croydon 020 8763 2586
- WISTERIA LODGE (Physical & Learning Disabilities) Nutley, Nr. Uckfield 01825 714080

For further information or to arrange a visit, please contact Corrine Wallace,
Head of Operational Care Services Tel: 01403 217338 • Fax: 01403 219842
email: corrine.wallace@sussexhealthcare.co.uk www.sussexhealthcare.co.uk



INVESTOR IN PEOPLE



Our champions say...

Here's a selection of Legend nominations from some of our reporters and writers



Andy Pickett, Disability Now columnist

RACHEL HURST has been a political disability activist for several decades, including in the British Council of Disabled People and the campaigning alliance for civil rights, Rights Now. Her day job for many years was as Director of Disability Awareness in Action with its leading role in championing disabled people's rights internationally.

She was a leading political operator over the last 12 years at national level championing the voices of disabled people and disabled people's organisations, and jointly convinced the Minister for Disabled People to have regular meetings with the movement from 2001. She played a leading role in supporting Scope to change to become an ally organisation.

She has persistently emphasised the human rights elements of disability equality as tenaciously as a rottweiler, and the parallels between the disability and anti-apartheid movements.



Cathy Reay, reporter, Disability Now

At the tender age of 20, **IAN CURTIS** brought together two strands of music, post-punk and digital, and started a movement that went on to rebrand rock and roll as the world knew it. His image,

his style, his voice, his outlook on life, were imitated by thousands, especially after his death. He worked inexplicably hard to follow his dream of becoming a punk rock icon, so much so that when he started having epileptic seizures on stage he wasn't deterred, he fought through it; his seizure-like movements even became part of his signature live persona. Ian Curtis may not be your typical disabled legend in that he didn't try to change the world for disabled people, but his suicide was a devastating

blow, though it did expose the world to Joy Division's music. And it showed that even the coolest looking kids in rock and roll had to battle against all odds to get there.



Peter Beresford, Disability Now writer

T E LAWRENCE (of Arabia) is the first truly modern hero. A man attacked for his sexuality, who experienced major breakdowns working for the liberation of Arab peoples. But even more than

that and why he is so important for our age, he valued the causes of both Jews and Arabs and worked for the rights of both. They might be living together in peace in the Middle East if his and their ideals, rather than the ambitions of empires, had triumphed. He was amazingly ahead of his time. His life is a beacon for survivors like me, arriving at a self-understanding through valuing the ordinary things of life and the ordinary virtues of other people – without judging.





Paul Carter, reporter, *Disability Now*

"Hero" is a word often overused and tossed around flippantly in today's celebrity-obsessed society. However, even by lesser standards, few can argue that **DOUGLAS BADER** is a rightful holder of that title.

Disability campaigners often like to shun "triumph over tragedy" stories, and in many cases are right to do so. Except that in Bader's case, his achievements and the obstacles he overcame were so remarkable that I unashamedly make an exception. You see, Douglas Bader was a war hero first, and a disabled person second.

Bader lost his legs before the Second World War, when he crashed an aircraft attempting to perform a low-flying acrobatic manoeuvre. However, after the outbreak of war, he passed refresher flying courses and soon progressed to flying Spitfires and Hurricanes in the Battle of Britain. In total he shot down more than twenty German aircraft.

In 1941, Bader's aircraft was shot down over German-occupied France, where he was captured. Despite mobility difficulties, he attempted escape several times, and proved such a nuisance to his captors that he was eventually sent to high-security Colditz Castle, where he remained until 1945.

After being freed from Colditz, Bader requested a Spitfire so he could rejoin the war yet again. His request was refused.



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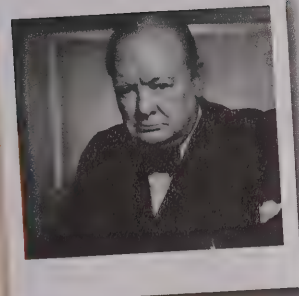
Penny Batchelor, travel writer
Disability Now

As most A-level English literature students can tell you, **SYLVIA PLATH's** poetry broke new ground in the 1950s and 60s. Her confessional style chronicled vivid and disturbing renditions of mental illness, with poems such as *Ariel* and *Daddy* containing searing, genius images of depression. Plath's autobiographical novel of her breakdown, *The Bell Jar*, is still a feminist rite of passage text. "Is there no way out of the mind?" she wrote. Nearly 50 years after her tragic, untimely death her gift with words is still firmly in ours. Plath put mental health issues on the literary map.



Ruth Patrick,
Disability Now
columnist
WINSTON
CHURCHILL

called upon the people of Britain to fight the Nazi enemy "on the beaches, in the fields and streets", never to surrender, and helped keep a country united during the tragedy and devastation of World War II. Churchill and his fat cigar are part of this country's cultural history and he is rightly regarded as a fine orator, a great leader and a champion of the British nation. Less well known, however, is his ongoing battle with his "black dog": depression, which he lived with throughout his life. Churchill shows what all of us in the disability movement know: that impairments are no barrier to success and greatness. ■



Read all our champions' Legend nominees at disabilitynow.org.uk

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Taking back **our lives**

“I went up to him on one occasion to put my arms around him and he just walked across the room, dragging me across the floor”

Attacked, afraid, abused but not alone: twice as many disabled women in the UK experience domestic abuse compared to non-disabled women. It's time to start talking about it. **Cathy Reay** meets four women that never imagined they would be made to be afraid to stay at home

Research published by the charity Women's Aid last year uncovered the reality that disabled women are twice as likely to be on the receiving end of domestic abuse and that, furthermore, their disabilities are a vulnerability abusers manipulate in their attack. For Holly, who has cerebral palsy, walking away from her abuser, from her family life, wasn't exactly easy. She and three other women have chosen to tell *Disability Now* about their experience of domestic abuse not because they want sympathy, but because they now realise how crucial it was that they sought and found a way out. Here are their stories.

HOLLY

For 12 of our 15 years of marriage my husband made me feel like I couldn't do anything right. He wouldn't let me spend time with my children except to feed them. He always bullied me in a disablist way.

Two years ago I found out he was having an affair with a friend of mine. I found texts on his phone that described me as a "bitch". It devastated me but I loved him desperately and wanted to make it work.

He started pushing me over around furniture so I would fall over it. He came to the house once and jumped

me while I was in the shower. I consented to having sex with him but at the same time I knew he was only doing it because he had physical power over me, I couldn't have said no if I wanted to. I felt used. I got so upset that he used my disability to his advantage however he wanted, to jump on me, undermine me in front of the children, hurt me.

I went up to him on one occasion to put my arms around him and he just walked across the room, dragging me across the floor. Another time he pushed me against the conservatory wall, holding onto me by my neck, and said "it won't take much to kill you, I'll just break

your neck, I don't care".

Meanwhile, one of our neighbours started coming round, being handy with housework, then one day he suddenly forced himself on me. The man was a friend of my husband's and helped him to fabricate an affair between us so that my husband would get child custody. Luckily he didn't.

I fled to Refuge with the children and it has come out my way but it has taken three years. The children and I are still healing. It was difficult at first to find a disability-accessible refuge that would take me and the kids but I'm glad we left and it's finally over.

SASHA

We started going out together when we were teenagers; things were fine for a long time, although I thought he could be a little possessive sometimes when I was on the phone to friends.

When I got pregnant he seemed happy about it but his behaviour got worse. He started slamming things whenever I was on the phone. He made it hard to have friends.

My arthritis got worse during the pregnancy and he started doing things to inconvenience or trouble me

as my health declined. For example, he knew I couldn't stand fish, so he would cook it and I'd get physically sick. I felt trapped, I had no say in anything. He would find reasons for me not to leave the house; he wouldn't even let me pay for a taxi to take myself to the shops.

The more I pulled away the worse it got. When I was five months pregnant I had a doctor's appointment and on my return I went upstairs to lie down. He came home and dragged me out of bed, yelling at me "where have you been?...who with?" He was intimidating; he never

laid a finger on me but managed to frighten me. He'd later say "but I never hit you" as if that made everything okay.

By then I'd started reading stuff on the internet and identified our relationship as abusive, and I knew I had to end it. I called Women's Aid for advice on how to escape.

I got a hostel arranged through the council, which is where I had my baby. It was miserable. But I came from an abusive background and I was damned if I was going to have a daughter grow up in that environment.

It isn't just partners that abuse. Children can find it hard to grasp why and how their mums are physically, mentally and/or emotionally different, why they're not like the other dutiful mums waiting in the playground. They may be bullied by the other kids in the playground, they may feel neglected or overworked at home. But whatever the reason, mums Tina and Jasmina found that it is easy for their kids to become abusive and very distressing if they do.



JASMINDA

After my husband died I realised I couldn't stand up for myself in front of my verbally abusive son anymore. He constantly called me names like "pussyhole" or "cunt", told me I have no friends and that I'm a druggie for taking prescribed morphine.

I was grieving and felt far more vulnerable to my son physically attacking me after my husband wasn't around. I became withdrawn and whenever he confronted me I would go to a friend's house or just leave the room.

I couldn't talk to my son, he never thought he had a problem, it was always me. He knew I was vulnerable and would go in for the kill with things I was sensitive about.

I go to a daycare centre and eventually I just broke down in front



TATYANA GRISHINA

of them. The manager told me it had to stop. I joined a vulnerable adults group at the Ealing Centre for Independent Living, who helped me start court proceedings against my son as he refused to leave the house.

My son failed to turn up to court so his eviction notice was served to him. Since then he's visited me a couple of

times and he's admitted that he needed that to happen and that he needed to see the outside world.

Disabled people are very vulnerable but there is help out there and we should seek it. You might feel you're going to be lonely but it's better to be lonely than to be scared in your own home. I felt isolated but now I feel free.

TINA

It all started after I had a heart attack. She saw that I was weak; the mum that she used to watch go to work every day wasn't as strong as she used to be. It's as if she resents the weakness, she wanted a strong mum, physically and emotionally, and suddenly she didn't have one.

Whenever she didn't get her own way she started to break things, smash stuff up, and push me around. She once called me from home, threatening that unless I returned immediately she would smash

everything in the house. When I walked in I nearly dropped dead: CDs, laptop, plates, everything was shattered.

I felt threatened; I had to get out for my own safety. I called the police but I felt too bad to press charges. She was so apologetic, she cried and said she was sorry a million times, but no matter how genuine that is sometimes all she sees is red.

A few days later she threw an ornament at a wall. She has punched me twice, outside the front door and once outside her grandmother's house. At her grandmother's she had me by my hair and I just turned to her

and said: "Why are you doing this?"

At 16 my daughter is stronger than me, and that is really frightening when she's so temperamental. But I forgive her every time because I feel sorry for her. I'm conflicted by my love for her and my need to feel safe in my own home.

Nowadays I won't show any weakness. Whenever she attacks I simply tell her I can have her removed from the house, that I can stop her from coming over. She lives with her grandmother now and visits me on weekends. It's hard but it's necessary, I'm stronger now because she's not with me. ■

All names have been changed. If you would like further information or advice on coping with domestic abuse visit womensaid.org.uk or call 0808 2000 247.

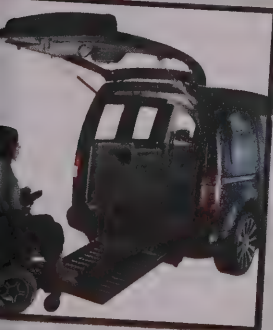
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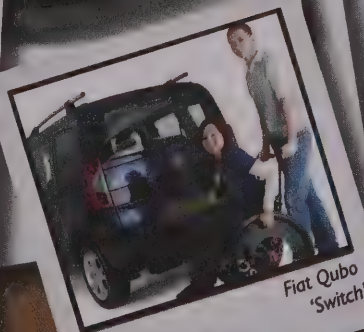
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yourviews

No single way to campaign

I was disappointed to see, in the March 2010 edition of *Disability Now*, direct action advocate Mandy Redvers-Rowe ("Taking it to the streets") and Jaspal Dhani ("Unity key for Council's new chief") of the United Kingdom Disabled People's Council (UKDPC) arguing against each other on different ways of achieving disabled people's equality.

Over 15 years, I have campaigned on a wide range of issues, from implementing the UN Convention on the Rights of Persons with Disabilities and anti-discrimination legislation right through to disabled people's equal rights to life, independent living and mainstream education.

During these campaigns I've had some memorable experiences of securing disabled people's rights through direct action, representing disabled children in courts, advising on legislation and policy, and doing deals with government.

The most significant victories were won when disabled people engaged in different ways of campaigning. We must



**Top: Mandy Redvers-Rowe;
below: Jaspal Dhani**

never forget that we needed our Disability Direct Action Network (DAN) actions in order for groups such as UKDPC to get at the table during our struggle.

When I was UKDPC campaigns officer, I was delighted to lobby the Labour Party conference at the same time as DAN targeted Tesco. While we

couldn't halt the welfare reform agenda, we managed to persuade the all-party Joint Committee on Human Rights to advise government that its welfare reform regulations might breach disabled people's human rights. This wouldn't have been achieved if we hadn't combined direct action with policy work.

And in 2010 we needed DAN actions again when the Equality Bill Committee refused to take evidence and suggestions from our groups, preferring to deal only with longer established disabled people's organisations.

I therefore look forward to direct action being taken outside government offices if after the election a Conservative education minister refuses an application to shut down a special school so resources can be transferred into a mainstream school. I'm also looking forward to negotiating with government to secure inclusive education rights.

Long live the different ways of campaigning. We need everyone to be there in any way they see fit.

Simone Aspis, by email

Student loans firm's bid for "quick fix"

I wanted to get people's opinions on the recent proposal by the Student Loans Company (SLC) to offer standard packages without a needs assessment for dyslexic students.

Given SLC's inability to cope with applications, as reported by *Disability Now* ("News Update", March 2010), it would seem to me that it is in search of a scapegoat and it would seem that course-related needs assessments are it.

As a dyslexic myself and having been through the Disabled Students' Allowances process, I find the matter distasteful to say the least. Organisations such as the National Association of Disability Practitioners and Skill: National Bureau for Students with Disabilities have expressed their concern but my worry is that this is going to pass under the radar and that the guidance is going to be changed in the SLC's bid for survival.

Jamie Prangnell, by email

Beware imitations

Can it be true? Heather Mills wanting to put Eamonn Holmes in a wheelchair in the interest of reality TV? No wonder she feels like the most hated woman in Britain.

Ted Ori, by email

Mothers and babies 1, Disabled drivers 0

I travel up and down this country on holiday break weekends in between hospital appointments. I've noticed year after year especially at a lot of Tesco stores in the south that they've been putting mother-and-baby bays each side of the door for easy access, and in some cases calling them "Mother and Baby Club".

The disabled, by contrast, are made to negotiate crossing the car park roads to enter stores and again after they leave. That's not very disabled-friendly, considering there's no legal requirement for mother-and-baby bays, which are abused by parents with no children under seven. (Look for the compulsory child seat. It's a giveaway.)

Before they start fining disabled people for using mother-and-baby places, supermarkets should start fining the abusers of disabled bays, I say.

Stop holding back because you are afraid you'll lose customers. You're losing customers of the disabled variety who are sick to the teeth that none of the big boys or their managers will go the full mile to stop all this discriminatory abuse.

Chris Potkin, by email

I found John Jewitt's ideas on designated parking spaces unbelievably ignorant ("Your Views", *Disability Now*, March 2010). He seems to think that disabled people use disabled spaces for convenience, but for most of us it's a necessity, not a luxury.

If you're a wheelchair-user and unable to walk, you can't use an ordinary parking space. On occasions I've had to abandon my shopping trip because there were no suitable disabled spaces left and I couldn't get out of the car. Parent-and-child spaces are for convenience only, and quite different. They have a choice and can park elsewhere: we don't!

Elaine Rush, Eastleigh, Hants

I totally agree with John Jewitt about disabled people parking in child-friendly bays. What gives us disabled the right to park in a bay that's solely for the use of people with children? We rightly get angry when Blue Badge bays are misused but that doesn't give us the right to misuse other bays.

Trying to get a child out of a car seat in a narrow space can be very trying. You need the pram handy, not stuck in the back of the car, and you need room at the side of the car for safety and ease of lifting.

Marion Jackman, by email

Manchester man was victim of "hate killing"



MARK ST GEORGE/REX FEATURES

It's been widely reported that the death of David Askew was caused by the "abuse of youths" over several years. Surely this is a hate crime and should be treated as such.

Chris Channon, by email

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Dancing to the funders' tune

Big funders favour big traditional charities ahead of disabled people's organisations, says **Andy Rickell**

I was asked recently if major social funders are biased towards traditional disability charities and against radical organisations led by disabled people, DPOs. The general answer is yes, with bells on.

When I was CEO at what is now the UK Disabled People's Council (UKDPC), there were three national funders that actively supported DPOs – the Big Lottery, Comic Relief and The Platinum Trust – essentially because they understood the importance of disability as a civil rights issue. Thank God for them!

The much bigger funding prizes come from central and local government, and via other funding schemes like Futurebuilders. These distributors of government funding ought to be keen to fund DPOs because DPOs have been and are leaders in the field of advancing disability equality, a stated Government goal. But DPOs report that they struggle to win funding, even obvious funding like for direct payments support schemes in their own local

authorities. Why is this?

Well it's because of what I call the "government funding dance" that all applicants for government funding must take part in. This "dance" involves masses of paperwork, proof of financial soundness,

DPOs do need to ensure they have sufficient business skills so they can make sound cases for public funding

proof of effective delivery. This "dance" therefore massively favours the larger organisations who can employ the fundraising staff, who can show financial soundness because of their large size and reserves, and who have a long history – which traditional disability charities can demonstrate more easily than their newer and smaller DPO rivals. Worse, in this "dance" equality is proven by a wonderful "equal opportunities" or "user involvement" policy rather than the obviously tangible proof of a DPO clearly led

by disabled people. Some of the worst disability organisations have the best policies!

It does not have to be like this. Often there are government rules which allow funders to proactively fund DPOs without having to go through this "dance", but it requires real courage and insight from civil servants to push these initiatives, and their bosses should encourage this more.

Furthermore, DPOs do need to ensure they have sufficient business skills so they can make sound cases for public funding – civil servants do have an obligation to show public money is well-used. It follows that government has an obligation to proactively support the capacity building of DPOs so they can acquire these skills – Disability LIB and the Office for Disability Issues providing capacity building initiatives to

User-led Organisations is a good example.

Additionally, traditional disability charities can choose to use their funding clout to support DPOs as allies rather than working against them – and the Disability LIB case where Scope supported the alliance led by DPOs to win £4.2 million is a good example.

Finally, there needs to be strong regional and national advocates of the key role DPOs can play. In my part of the world that means the development of the regional South West Disability Equality Network of DPOs, and nationally through umbrella organisations of DPOs like UKDPC and the National Centre for Independent Living (NCIL). Such organisations can be DPOs' trade organisations, pushing our trade of social change via campaigning and/or service delivery.

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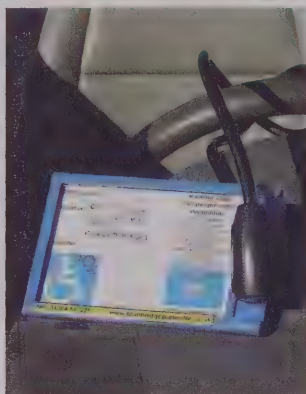
Occupational therapist with interest in housing

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HELEN SMITH

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Blue Badge space legal entitlement



Q My wife is disabled with very bad legs, she is unable to walk very far, we live in sheltered accommodation and our car park is limited to four

people to six bungalows. We have asked Wycombe District Council to mark a space with our house number but they flatly refuse. Does she legally have a right to a space, or should we pursue the matter further?

J Rockell, by email



Helen Smith replies: If your wife has severe

difficulty walking she may be entitled to a Blue Badge so the first step I would take would be to

apply for one of these.

Your council may agree to mark a disabled bay outside your house but it would not be only for your use as anyone with a Blue Badge would be entitled to park there. However, some councils are now asking for a contribution to mark out these bays and others have stopped doing it all together. There does not seem to be any legal obligation on councils to provide disabled bays outside people's homes.

Am I entitled to Road Tax exemption

Q I refer to the website directgov which gives the conditions for free road tax for disabled drivers. I do not receive disability allowance (I am 79 and receive Attendance Allowance because of my disability), nor do I get the war pensioner's mobility supplement. However, I have a mobility scooter.

On contacting the government department the person I spoke to did not seem very sure about the conditions for road tax exemption, but seemed to think that in order to qualify ownership of a

scooter had to be linked to one of the other conditions.

I am only able to walk a very short distance and when I am out it has to be by car or scooter.

Ian H Kemp, by email



Helen Smith responds: I'm afraid that even though you are a

disabled person who uses a mobility scooter you do not qualify for road tax exemption. This concession is only available to people who receive the Higher Rate Mobility Component of Disability Living Allowance (HRMCDLA) or War

Pensioner's Mobility Supplement (WPMS). I'm afraid that Attendance Allowance (AA) is not one of the qualifying criteria as it does not contain a mobility component. You can only claim HRMCDLA if you became disabled before you were 65 and many older people are in the same position as you. Mobilise believes this is age discrimination and is totally unacceptable.

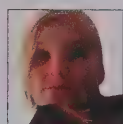
I don't know why the person in the government department was unable to help you but if you need more information visit direct.gov.uk



Getting into podcasts

Q I have always been an avid radio listener. Often, though, it's not possible for me to catch all the shows I want to hear. I'm aware that many of these, along with many others from places other than regular radio stations, are available for download from the internet as podcasts. Could you give me a beginner's guide on how to start listening to these? Can they be put on to an iPod or other MP3 player? Do you need additional software for doing this? And how accessible is the process for anyone using a variety of

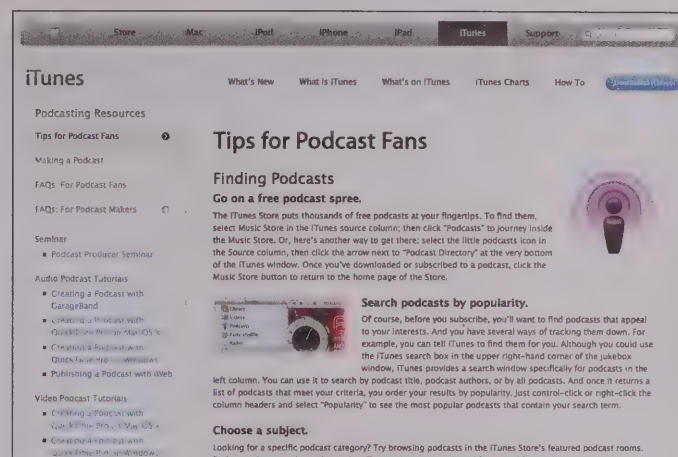
adaptive technologies?
A Hillman, North London



Léonie Watson says: Podcasts are usually provided in MP3

format, so they're perfect for transferring to an iPod or MP3 player. The idea is that you subscribe to a podcast, which means you're automatically alerted when a new edition is available.

You'll need some software to manage your podcast subscriptions, but there are plenty of options available. Like podcasts themselves, most podcast software is



free. Your choices include iTunes, Google Reader, Juice and My Yahoo!

The process of subscribing to a podcast is simple, but there are several ways you can approach it. Let's take iTunes as an example and go through the different processes.

You can search for podcasts using iTunes. Select the "Music Store" from the iTunes source column, then select "Podcasts". When you find one you're interested in, you can select it to listen to a preview, or use the "Subscribe" button at the top of the page to sign up.

You can also subscribe to a podcast directly from a website. The BBC, for example, include quick subscribe links for several popular podcast applications

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pete's place

Chickens coming home to roost



With "personalisation" coming down the track, **Peter White** believes there may be a credibility gap between the vision and the reality

Whenever I hear the term "personalisation", I'm irresistibly reminded of Alan Lockett and his chickens.

Alan was a guy who'd lost his sight in his twenties, but came from a bit of a farming background. He wanted to work, but no way did he want to do any of the stock jobs available then

for blind people. He wanted a chicken farm, and one way and another the local blind society, then still acting as agent for the social services, helped him get it: a mixture of tapping up what income streams there were, plus loans, plus the begging bowl and the Round Table! And, he made a great success of it. Basically, it was

personalisation: circa 1954! So it's extraordinary that it took until about 2008 to give it a fancy name, and wheel it out as a brand new policy.

Still, no need to carp; surely! We've finally got there: government handing down the tablets of stone: let personalisation and individual budgets multiply (except that the money in the budgets won't multiply, of course). But the question which has to be asked is: can it work, when you're essentially grafting it onto a system which for so long has

operated on the basis of: "here's what we provide" and "we know best"? It's a big leap from that to: "I want to appoint my own care staff; I don't want to go to the day centre; oh, and by the way, rather than therapeutic Sunday morning swimming, I'd rather have someone to come with me, watch the Saints on a Saturday afternoon, and have a couple of bevvies afterwards because, actually, that will do more for my sense of well-being". The problem is: I've now been to numerous conferences entitled "personalisation: what is it and how will it work?"; and the gulf between the theory and the practice is alarming! To exercise choice effectively, you have to know what the choices are; and, especially if you're new to disability, or if you've always had your choices defined by other people, you rely on someone to help you discover what those choices are. Do we have a workforce, and a mindset, that's going to make that possible? My conferences don't reassure me that we do: especially, and here's the elephant now in every room, when the budgets are going to be cut to the bone.

ed cetera



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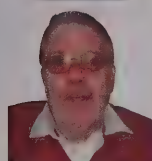
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guestcolumn

Laying bare the care scare



OLIVIER LE QUEINEC



Veteran activist and academic **Mike Oliver** says it's time to debunk a few of the myths currently being pedalled by politicians of every stripe

Over recent weeks in the run-up to the General Election we have seen all three parties announce their plans for care in respect of elderly and disabled people. One lot have already ratted on their promise to provide free care for all; another propose a voluntary insurance policy of £8,000; the third a compulsory payment of £20,000.

It is impossible to make sense of any of this however because it is difficult to detect any serious thought or sensible policy behind all the posing of our politicians. Perhaps it's time to remind our

political masters that these issues are too important to us to be reduced to political opportunism and juvenile behaviour more appropriate to a public school debating chamber than a supposedly democratic society.

It is not as if people being forced to sell their homes to pay for care is anything new. Local authorities have been selling people's homes against their or their relatives' will since 1948. I know when I worked for a social services department in the late 1970s, we were "at it". Local authorities are still selling people's homes today too and nobody is even talking about it.

Nor are we suddenly going to be hit by a tidal wave of dependency; an elderly tsunami if you like. When I was a student 40 years ago we were taught about the ageing population that was going to pose issues for future economic and social policy and it has been talked about constantly since. The tide has been coming in slowly so why have successive governments not been planning for it?

Most dangerous of all we are constantly being told by politicians, economists, media commentators and the other self-appointed experts is that we cannot possibly afford the rising cost of care. Many of us have even come to believe it ourselves.

I don't remember any debates about whether we could afford it when the warmongers amongst us decided to bomb Iraq into submission or when the financial apologists decided to bail out the reckless gamblers who nearly wrecked our banking system.

It is the biggest and most

dangerous omission from the debate about care of all. It means we have to put up with invasions of our privacy, the possibility of legal action to take our homes and even future imprisonment in some kind of residential establishment.

It is not as if people being forced to sell their homes to pay for care is anything new. Local authorities have been selling people's homes against their or their relatives' will since 1948

But it is even more dangerous than that because it devalues our lives and points down the road to terminal neglect, accelerated death, do-not-resuscitate policies and assisted suicide. As a disabled person I used to be just scared of the future. Now I'm officially old as well, I'm bloody terrified.

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upclose&personal

DNR – clear and present danger

“Do not resuscitate”, DNR is what medical staff write on the notes of those people whose quality of life they judge to be so poor as to be not worth striving to save. It’s also a judgement which can cause disabled people like **Anne Pridmore** to be genuinely afraid of going into hospital

Three years ago I sustained an injury to my leg resulting in me having to go to the A & E department of my local hospital. One of my Personal Assistants (PAs) felt unsure how to stop the bleeding so she called on one of my other PAs to accompany her to the hospital. Whilst waiting to be seen by the doctor I overheard my PAs discussing whether one of them should fetch my night clothes. I felt out of control and very frightened because my experience of hospitals as a disabled person is far from good.

I have no family members who could advocate for me and this incident brought it home to me that I needed to set something in place if I ever ended up in hospital. I drew up a paper which gave clear instructions if the occasion ever arose where a doctor put over my bed “do not resuscitate” that unless I told them differently I wanted to be kept alive for as long as possible. I made all my Personal Assistants sign up to this. I also gave them



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I drew up a paper which gave clear instructions if the occasion ever arose where a doctor put over my bed ‘do not resuscitate’ that unless I told them differently I wanted to be kept alive

the phone number of a friend who has been charged with the responsibility of making sure this happens in the

event of me being unconscious.

Before I go any further, whilst not wanting to dwell on it, I do experience severe pain every day of my life. The ageing process does not help cerebral palsy and everything becomes more difficult. However, I know that this fact alone would never make me want to end my life. There are two important issues to consider here. The first is that our culture is encouraged in the tabloid press to see disabled people as tragic but brave, not full

and contributing members of society. Having spent the last 23 years campaigning for equal rights, locally, nationally and in Europe, and recently starting a social enterprise to support disabled people who employ their own staff, I feel I have been able to contribute in a positive way to support other disabled people. My second argument is that none of this would have been possible had I not an electric wheelchair, a computer, an adapted car and support from my local authority to employ my own Personal Assistants who enable me to take an equal part in society.

Being fully aware of the socio-economic climate I live in, where disabled people are seen as inferior to non-disabled people, my fear is not that I might find my impairment so painful that I would want to be helped to die but rather that in law I have no legal right to Independent Living and the support that enables me to contribute to society will be taken away.

I bought a lovely green jacket to go to the House to receive my peerage – only afterwards did I realise it's going to clash with the traditional ermine-trimmed, crimson velvet cape I'm renting for the occasion – but I really like the jacket so I'm going to wear it anyway and just close the cape around it for the ceremony!"

Dame Tanni acknowledges that colour co-ordinating has never been her strong point. As a teenager in the 80s, she would buy vibrant floral curtains from charity shops and use her sewing machine to turn them into trousers and skirts as well as embroidering jackets with colourful patterns and emblems. At university, she saw no problem with wearing ten colours at once even when fellow-students asked her if she really wanted to go out like that?!

However the Cardiff-born Paralympic star discovered that gold goes with everything when she started her sports career, accumulating a staggering 11 gold medals in five Paralympics. Perhaps the only person who was happy to see Tanni give up competitive sports was eight-year-old daughter Carys who thinks athletics is "boring" as "Mammy just goes round in circles".

Nowadays, soon-to-be Baroness Tanni is constantly in demand for her expertise promoting sports education with emphasis on disability equality and she's devised a cunning way to avoid those earlier wardrobe faux-pas.

"My work wardrobe is entirely black; I'm always travelling, packing and re-packing and it's too much hassle thinking about what goes with what so I take a few pairs of trousers, some polo-necks, a long fitted dress and some boots – all in black – and a big bag full of colourful, chunky jewellery. Then I just have to think about what colour accessories I fancy wearing to each engagement – pink, purple, silver



Tanni

on track for The Lords

Dame Tanni Grey-Thompson is one of the country's most influential women in sport today with a slew of Paralympic gold medals as well as an MBE, an OBE and a DBE to her name and she's about to become a Baroness with the power to vote and lobby in the House of Lords – but what **Lara Masters** really wants to know is; what is she going to wear

with cubic zirconium squares – I love sparkle and none of my jewellery's very expensive. Recently a woman asked me where I got one of my

necklaces from – she wouldn't believe that it was £5 from Asda!

"When I'm not working I wear a lot of sports gear and jeans. I love jeans. My



“None of my jewellery's very expensive. Recently a woman asked me where I got one of my necklaces from – she wouldn't believe that it was £5 from Asda”

husband keeps threatening to count how many pairs I've got. I love shoes too, although unfortunately I can't wear heels as I'm quite flat-footed and my ankles roll over, but I've got quite a collection of flat shoes which my husband did count the other day – apparently I have 48 pairs – but if I manage to find shoes I like that fit and don't slide off my foot-plates I'll get the same pair in black, red, blue and silver!”

Even a superstar like Tanni has the

same problems as many other disabled people when trying to find clothes to fit her shape and she's not exempt from body-image niggles either; “I'm a size 8 lower body but 14-16 upper body so I often have to get my clothes altered to fit me properly. I don't like the scars on my back so always cover those up and I'm bigger than I'd like at the moment. Although I push about six miles a day in my chair, I used to do 120 miles every week when I was training and could eat

whatever I wanted. These days it's hard to eat really healthily because with travelling so much I end up eating lots of sandwiches and wraps but I try and be disciplined; I love crisps – I could happily eat them all day long – but I don't and I don't drink.”

A little probing reveals that Tanni's abstaining is less down to discipline and more due to a low tolerance for alcohol – the last time she had more than a glass of wine was two years ago when she got very drunk at a parent-teacher meeting!

Reassuring as it is for us to have a teetotaler shaping our legislation in the House, I don't think anyone doubts that our champion Dame is match-fit and will be an exemplary peer and in her new role, she certainly won't be going round in circles! ■

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Come dive with me

Scuba newbie **Kathy Longley** tries her new-found skill in the Red Sea. She may not part the waters, but travels in the steps of Moses in Egypt

Did you know?

Coral is made up of colonies of tiny animals called polyps.

Submerged in the Red Sea at 12m fish swirl around me in a kaleidoscope of colours as I marvel at this new and exotic underwater world. Glancing down to the sandy bottom I see two blue-spotted rays playfully darting back and forth in what looks like a mating ritual. I signal excitedly to my buddy using my newly acquired underwater sign language, but he is absorbed with a huge potato cod he has discovered lurking beneath part of an old shipwreck.

When my partner, Paul, first suggested that we do a diving course I thought the stress of our upcoming wedding had addled his brains; how on earth did he think I would be able to dive? I struggle with hydrotherapy! He convinced me, however, to give it a go and before I knew it he was tugging me into a wetsuit, securing my fins and mask and lowering me into the swimming pool. Once in the pool I was loaded up with a weight belt, jacket, tank and regulator, ensuring that the water took the weight rather than my painful shoulder and back muscles.

Breathing under water for the first time is a very weird experience; you tend to want to breathe through your nose and have to keep reminding yourself that your air supply is attached to your mouth. Once you've got the hang of it though you're ready to start learning all the scuba-diving skills, the most important of which I soon discovered was neutral buoyancy. Neutral buoyancy means that you hang in the water at the level you want to be, without sinking to the bottom or rising to the top. The idea is that you can then drift along with minimal effort enjoying the underwater scenery, making diving an ideal sport for those of us with limited mobility.

Having mastered the basics in the pool, Paul and I jetted off to Egypt on



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Did you know?

Red and yellow light is filtered out by the water the deeper you dive, making everything appear bluish. To see natural colours divers must bring their own light-source.

honeymoon to test our newly acquired skills in open water. We signed up with a company called Camel Dive based in Naama Bay, Sharm El Sheikh. We were attracted to Camel Dive because they are the only centre in Sharm to have received the prestigious PADI Accessibility Award, which designates a centre as having a special commitment to divers with disabilities. In fact, the dive centre with its four-star hotel and restaurants was specifically built with disabled guests in mind, including wide corridors, lifts, ramps and five hotel rooms specifically designed for guests with restricted mobility.

Our instructor, Neal, was unfazed when I explained the additional help I would need with setting up my

equipment, putting it on in the water and breaking up the dive sessions over several days so I did not exhaust myself or increase my pain levels. We were keen to get started, but soon discovered that diving in the sea was a whole new ball game. Ridiculously, the fact that the sea is salty and in constant motion somehow takes you by surprise, and when combined with the strange, foreign surroundings and a depth that seems never-ending, it appears to wipe all those newly acquired skills firmly from your brain, leaving you bobbing up and down uncontrollably in the water absorbing precious air at a very rapid rate! Luckily, Neal was ready for this common reaction and soon had us floating along in a straight line pointing out colourful corals and fish for distraction. In a short time calm was restored and we became totally awestruck by this enchanting new world.

Our training all took place on the home reefs near the shore, but once we were qualified we were allowed to





Did you know?

The Catherine wheel derives its name from St Catherine who was spun on a spiked wheel before being beheaded by a pagan emperor.

head out to the world-renowned Ras Mohammed National Park. This involved dragging ourselves out of bed at 7.30am (not overly conducive to a honeymoon) to get to the harbour on time to catch the boat, whereas if you stay at the Camel Hotel you can simply walk or wheel yourself directly down to the jetty just five minutes away, and no doubt get an extra hour in bed.

I was lifted onto the boat by the crew

members and found that I could easily access the ground level, although there was not a disabled toilet on board. The crew and staff from Camel could not have been more helpful with helping me set up my equipment and performing a seated entry into the sea. This involved me sitting on the edge of the boat while they kitted me up and then held the weight of the tank while I slipped into the water. This turned out

to be easier than putting the kit on amongst the waves. Once under the water the weightlessness is simply a joy as the current gently moves you along leaving you free to simply look around and marvel. If you need to swim then your fins or the alternative of webbed diving gloves make it a breeze. Much less effort and far more fun than hydrotherapy! I can certainly see why people with disabilities love this hobby and return to Camel Dive year after year. I just hope on my next excursion that I actually get to see a turtle, as among all the amazing things we saw they were decidedly lacking.

Of course diving is just one of the activities Egypt has to offer and if you're looking for a contrast head out into the vast desert areas. You can choose from a camel safari, sand buggy adventures or a trip up into the Sinai Mountains to stand where Moses received the Ten Commandments. As a visit to Mount Sinai itself involves

PAUL IP



PAUL IP

climbing 750 steps we opted for the next best thing, St Catherine's Monastery (pictured above), nestled at the foot of Mount Sinai and believed to be the site of the Burning Bush.

The scenery along the winding road through the desert is stunning with rising peaks of red rock carved into all kinds of fantastical shapes by the wind and sand. Interspersed among rock and sand are sporadic Bedouin settlements consisting of small brick houses and a handful of camels. Stopping to admire a viewpoint, we were met by inquisitive Bedouin children and men in their traditional garb selling pottery and jewellery. Despite their fairly shabby

appearance, we were warned that the Bedouins are not as poor as they may appear as many of them now work with jeeps rather than camels and make a good living from the tourist trade.

St Catherine's Monastery is still inhabited by monks and therefore is only open in the mornings and has restricted viewing. It is worth coming for the scenery alone and the absolute silence you can find if you wander a short distance away from the main tourist areas. The inside of the monastery is not accessible by wheelchair, but it is such a small area I was able to walk around it. You can see the Well of Moses, the Chapel of the Burning Bush and of course the famous bush itself which is said to be evergreen and not possible to cultivate outside of the monastery. We were entertained by the many pilgrims trying to surreptitiously break off twigs as souvenirs and hiding them in their bags before they were spotted by officials.

In my opinion a trip to Egypt would not be complete without seeing the pyramids and Sphinx, so we booked ourselves on a day trip to Cairo, only a 45 minute flight from Sharm. I was totally awestruck by these ancient monuments rising majestically upward toward the sun and was quite happy to just sit there and

gaze at their magnificence. Not that you get much opportunity to sit quietly, as within about 30 seconds you are being accosted by children trying to sell you cheap postcards and plastic pyramid models or assailed by Egyptian men determined to get you up on their camel. We were strongly advised to avoid all such temptations and politely refused all offers while we fought our way to the foot of one of the pyramids to lay our hands reverently on the ancient rock.

Cairo itself is a rather manic but exciting city with people everywhere, pushing and jostling their way along. I was astounded at how people quite calmly risk their lives by walking out in front of the crazy zigzagging Egyptian drivers in an attempt to cross the road. The Museum of Antiquities is well worth a visit, but be prepared for long queues and elbow fights to see the treasures of Tutankhamun.

Overall for me, Egypt is a land of exciting contrasts where you can experience vast desert, ancient history and the spectacular underwater world; it has something for everyone and is well worth a visit. ■

INFORMATION

Rates for PADI Open Water course plus accommodation at Camel Dive (pictured left):

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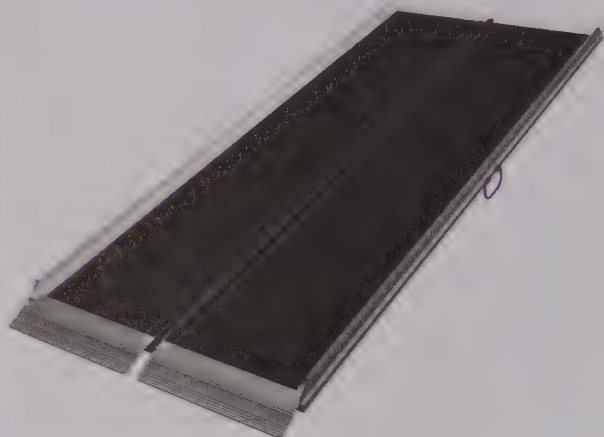
Camel don't sell flights but packages for Camel Hotel + flights + diving are available from Scuba Travel (and can sometimes work out cheaper): scuba.co.uk.

Note that it's always cheaper to book the diving course in advance.



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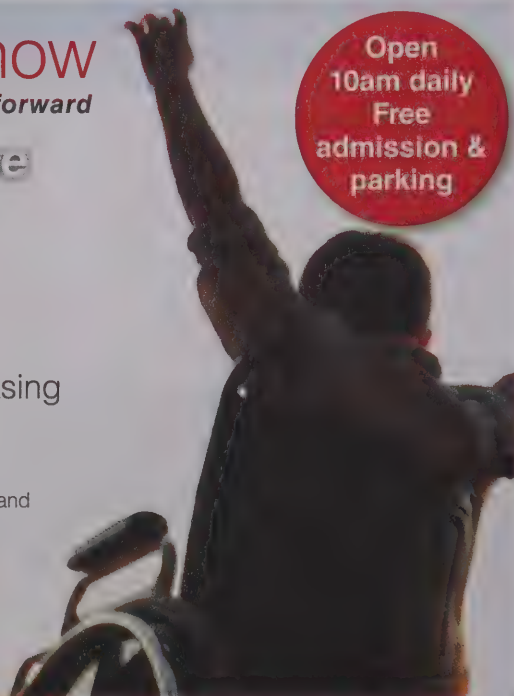
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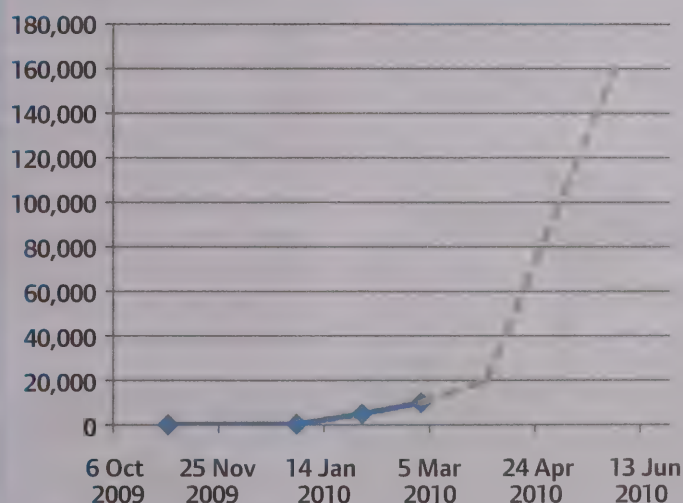


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You too can YouTube

Content-sharing site YouTube has enabled people to share magic moments, material from entertainment archives and more informative video. But it's a part of the internet that's remained closed to some people. Until now. **Edmund West** reports



YouTube's graph reveals an ambitious prediction for the growth in the auto-captioning of its users' videos. The blue line shows actual growth to date; the dotted line anticipates 160,000 subtitled videos by mid-June of this year.

A major complaint among groups of disabled people, particularly those with sensory impairments, is that all too often the technological revolution leaves them behind.

One area where this has been evident is in content sharing: how, for instance, could a deaf person use – fully access the wealth of video content on YouTube?

After years of lobbying,

auto-captions, also known as subtitles, are becoming a universal video feature. YouTube, having introduced them gradually, began extending them to its whole site on 4 March.

Its UK communications manager, Oliver Rickman, explained: "This is part of an ongoing process. One of the first steps we took was the development of a caption feature in 2008. In November of last year we

released auto-captioning for a small, select group of partners."

These first auto-captions were for a few educational videos; now they're being released for all. That means that anyone uploading content to the site can request captions for it, which YouTube will provide.

The captions use automatic speech recognition (ASR) software to caption submitted videos on request. It works in the same way as Google Voice and Google's speech-to-text voice search on mobiles. If a video has a CC button, click it and you'll have a "transcribe audio" button for English captions and a "translate captions" button for other languages. You can even alter the font by clicking the "other settings" button.

Asked about the project's next stage, Rickman said: "We're working on improving our underlying ASR technology, with a focus on improving performance as well as expanding to other languages. Our research includes a focus on expanding our ability to handle a wide variety of material (e.g. different speaking conditions and accents). The ultimate goal, though we don't know how long it

will take to get there, is to make this feature available for all videos in all languages."

YouTube has a queue of people asking for their videos to be captioned early. Captioning content takes anything from an hour to a day.

With more deaf than Italian-speaking internet users, the impact of this technology could be vast. There were many calls from deaf people for this feature, Rickman said.

"Information access is core to our mission. We want to make information universally accessible and useful, and that certainly includes people with disabilities, such as blindness or low vision, colour deficiency, deafness, hearing loss and limited dexterity."

Another group who could use captions are hearing people learning sign language.

Oliver admitted the system had its limitations. "Different accents, background noise, and audio quality levels present interesting challenges that we're working to address as we improve our ASR technology."

Maybe in the future, those improvements will extend to areas such as audio description for visually-impaired users.

Scooters - accidents waiting to happen



As the Government embarks on a review of their use, **Helen Smith** says it's high time scooters and their owners were subject to more regulation

Driver who killed pensioner in mobility scooter hit-and-run has never been traced...

Police powerless to prosecute hit-and-run pensioner who left girl, 2, seriously injured in mobility scooter collision...

Grandmother dies after being knocked down by hit-and-run mobility scooter.

These are just a few scooter headlines making the news over the past year. Unfortunately a small minority of bad drivers are giving mobility scooter users a bad name. This is not helped by the fact that anyone can just go out and buy a scooter or powered wheelchair without an eye test, a driving test or purchasing any kind of insurance. Currently the only requirement is for mobility vehicle users to

register with the DVLA – a pointless exercise in my opinion when there is no requirement to even display a number plate. There is also very little redress if anyone is caught driving

badly or dangerously. In fact, the law used to prosecute drunk users is an Act from 1872 “drunk in

charge of a carriage” so some form of update is well overdue.

Accidents involving scooters are increasing and both national and local papers are full of mobility scooter incidents. I have myself been involved in such an accident when an elderly lady on an enormous yellow scooter forgot how to break and drove into me and my mum in the supermarket queue. Being in a wheelchair I was OK but my mum suffered severe bruising to her leg.

I was therefore pleased to hear that the Department for Transport has announced a consultation on proposed changes to the laws governing the use of powered mobility vehicles and powered wheelchairs, as I believe that there needs to be some kind of basic driving and eyesight test and at the very least third party insurance. The consultation which ends on 28 May is asking for people's views on possible changes to existing legislation. The main areas that the consultation is looking at are the legal classification; design standards and safety features; possible reforms relating to vehicle users including training and fitness to drive, insurance



and the registration of mobility vehicles.

Anyone who has borrowed a scooter from Shopmobility would have had an assessment and many also do SUPA (Scooter User Proficiency Award) tests for people who have their own scooters. I would expect if a test was brought in it would be something similar to this. I personally would be happy to take a test and have insurance as I'd rather pay a small amount now than risk being sued by someone who claims I'd run into them.

An elderly lady on an enormous yellow scooter forgot how to break and drove into me and my mum

This is a view supported by Janet Sutton who is a trustee of Mobilise and Chairperson of Shopmobility Stockport. She said: "Due to an increase in accidents involving scooter users, some of which have unfortunately been fatal, scooter users need to be

able to show their fitness to drive, including vision, concentration levels and medication and that they have a vehicle type that is suitable for them and their needs."

However, some people feel that more legislation is unnecessary and it could reduce someone's mobility if they failed the test. I recently had a lively debate with Brian Coleman who is the London Assembly Member for Barnet and Camden on BBC Radio 2. He said: "The Government and voluntary sector just

want to introduce rules and regulations."

However, I think in this instance they are actually required. If someone has very poor eyesight and is unable to control the machine it's not right that they are able to injure someone and then drive off with no redress.

Anyone can respond to this consultation so if you have a view on mobility vehicles do let the Department for Transport know. Visit dft.gov.uk

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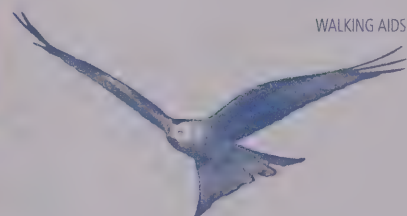
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sportnow

By Paul Carter



The 2010 Paralympic World Cup has received a boost as four-time Paralympic champion, Oscar Pistorius has confirmed he'll be taking part.

The new look event is also to feature a new sport and an amended format as preparations progress for the London 2012 Paralympic Games.

For the first time, 7-a-side football will be included in the schedule for the event that will once again be held across Manchester from 25 to 31 May, which is now firmly established as the largest annual international multi-sport competition in elite disability sport.

7-a-side football, which is

contested by players with cerebral palsy, is played on a smaller pitch and has no offside rule.

Competing alongside the Great Britain team will be teams from the Republic of Ireland, the Netherlands and the USA.

GB 7-a-side team captain Jordan Raynes said he was "very excited" that football would be featuring at the event.

He said: "I live and play in Manchester, where we have a strong following for our county disability league, and to now have an international competition in my home city means so much to me.

"To have an elite event outside of the Paralympic Games with other leading

football nations will be imperative to the team's progression as we look forward to the 2012 Paralympic Games, and look to build on our seventh place finish in Beijing in 2008."

Football will take the place at the event of track cycling, which ParalympicsGB said has been left off the schedule for 2010 to "enable other Paralympic sports to receive key competition and exposure in the build-up to London 2012".

Wheelchair basketball, athletics and swimming will all feature as usual.

There is also a change to the format from previous competitions, with Great Britain's athletes this year

competing on a team basis against Europe, the Americas and the Rest of the World.

Phil Lane, chief executive of ParalympicsGB said: "An exciting new team format has been introduced to promote elite disability sport on the world stage and will give the opportunity for the GB team to demonstrate their sporting abilities and take on the best of the rest of the world as we increasingly look forward to the prospect of a home Paralympic Games in 2012."

In a major boost to the event's popularity, four-time Paralympic champion Oscar Pistorius has also confirmed he will compete in the 100m and 400m track events.

"I'm delighted to be competing in this year's BT Paralympic World Cup," he said.

"The event comes at a key time in my season and I will be looking to set fast times in the 100m and 400m. The London Paralympic Games are just two years away now and to have major international competition in the UK is crucial in my preparations as I look to defend my Paralympic titles and also compete in the Olympic Games. I always enjoy competing in Manchester as I receive such great support."



KEVIN BOGETT-SMITH

McKeever, "Olympic dream over"

A Canadian skier's dream of becoming the first person to appear at both the Winter Olympics and Paralympics has been shattered after being dropped from the squad.

Brian McKeever (pictured above, right with his guide), who is visually impaired, had hoped to make history in front of a home crowd in Vancouver after being selected for his country's 50km cross-country skiing squad.

He had already become a national icon in Canada, appearing across news programmes and even featuring in his own

television advertisement.

However, just over a day before he was due to compete in his Olympic race, McKeever was told that he would not be one of Canada's entrants.

Each country is only permitted four racers in each race, and coaching staff opted for four skiers who had already performed well in other Vancouver events.

Canada's head coach, Inge Braten, said he had to put the interests of the team ahead of sentiment.

"I have to be professional. I have to choose the guys who are best for the 50K.

"Sorry to say, all four are

faster than Brian. And I think they can fight for a medal – all four of them. Do I then have to pick out one who has a medal chance and put in Brian?

"That's the situation. I don't like it," he said.

A post made by McKeever on Twitter simply said: "Olympic dream over. Don't think I've ever been so sad."

McKeever, who has Stargardt's disease, has only ten per cent peripheral vision. In Olympic events he skis alone, while in Paralympic races his older brother Robin, himself an Olympic athlete who represented Canada in the 1998 Winter Olympics,

acts as his guide.

It is reported that he even petitioned the skiing governing body, FIS, to make an exception and allow a fifth entrant for Canada to compete on home snow.

No such request was granted.

While several athletes have achieved the feat of competing in both the summer Olympics and Paralympics, McKeever would have been the first to reach the milestone in the winter equivalents.

However, he now turns his attention to the Winter Paralympics, in which he competes in five visually-impaired class races; three in cross-country and two in the biathlon.

entertainmentnow

Music on his mind

To people beyond the folk and roots cognoscenti, a new album from Texas-born Daniel Johnston may have little impact. But many recognise a unique talent and Johnston counts Tom Waits and Beck among his fans. **Sunil Peck** listens to his music and talks to him about his approach and his state of mind



TIM BRODDIN

Fans know Daniel Johnston as much for his depression as for his music.

His life and experiences were chronicled in a 2005 documentary, *The Devil And Daniel Johnston*. Widely seen as a sympathetic portrayal, it traces his dropping out from college, running away to join a carnival, trying to crash a plane his father was flying and his stays in psychiatric hospitals.

"They did exploit me a lot, you know; they always have. There's nothing you can do about that. But press is good press, I like to say."

Nevertheless, he does reflect on his depression in his music. Take the lyrics in the track "I Had Lost My

Mind" on his latest album *Is And Always Was*:

I was sitting in the basement when I first realised it was gone. Got in my car, went right over to the lost and found. I said, "Pardon me, but I seem to have lost my mind." She said, "Well, can you identify it please?" I said, "Why sure, it's a cute little bugger, about yay big, a little warped from the rain." She said, "Well then, sir, this must be your brain." I said, "Thank you ma'am, I'm always losing that damn thing."

Daniel has produced over 30 albums including songs covering, among other themes, his unrequited love

for a former classmate Laurie, demons and Caspar the Friendly Ghost.

Born in 1961 and inspired by The Beatles, Daniel began to attract fans in the early 1980s when he used to record, illustrate and hand out cassettes of his songs in Texas. Artists including Beck and Tom Waits are fans, as was the now-deceased lead singer of Nirvana, Kurt Cobain, who was often seen wearing a T-shirt with the cover image from Daniel's album *Hi, How Are You*.

To those and others in indie music circles, Daniel's songs about love and loss are the work of a genius. To the uninitiated, his songs can sound like the ramblings of a troubled soul. His vocals



DICK JOHNSTON

are sometimes piercing and the lyrics can seem out of sync with the guitar.

But everyone seems to agree that his music is raw and unproduced. When he plays in London at the beginning of April on his latest tour, he'll be joined by a Dutch orchestra. Its use of brass and strings as well as drums and guitars will be a musical departure from his traditionally low-fi sound.

"Usually I just play my guitar. Then my friend will come out and play guitar and I'll sing and then the band would join us. But we've got a trombone,



TIM BRODDIN

saxophones: it's hard to keep track. There was a lot of instruments. We had a practice a month or so ago. It was so cool. The rehearsal was a lot of fun and sounded great."

When we talk, Daniel is taking a break at home in Texas where he lives with his parents. He is fresh from a tour of Australia and Japan and is about to go back on the road in Europe.

"It was a lot of fun travelling around. I got a pretty good response in Australia so that turned out alright."



TYRON FRANCIS

He is looking forward to visiting the UK again because his gigs are usually sold out.

"It'll be the same old folk music, a little bit of

rock 'n' roll, you know."

Daniel has started taking different medication which is alleviating his depression. But is there therapy value in performing and touring as

well? "It does help out to be doing something rather than just sitting around in the house," he says.

Also artistic, Daniel loves drawing and is keen to combine more touring with producing more art in the future.

"I love to do comics and I hope to do some comic books some day, and I've had some offers. So I've been practising and trying to figure something to do some day."

• Daniel Johnston plays London's Troxy on 2 April

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Linking to a **brighter** future



Do you want to change the world or just have a burning passion that you want to share with whoever will listen? E-campaigner **Martyn Sibley** says there are now tools at your fingertips that really could enable you to leave your mark on the world

Just look at Obama. Thirteen million supporters on his email list, three million online donors, three million Facebook friends, a peak of 8.5m monthly website hits, 800,000 blogs, 35,000 volunteer groups mobilised to run 200,000 offline events and 70,000 fundraising hubs raising \$30 million. No wonder he made President!

But Obama's strategy is transferable to any cause or campaign. For example, a recent issue for disabled people was the potential of Attendance Allowance and Disability Living Allowance to be swallowed up by the new social care reforms. An online e-petition collected 23,710 names opposing this. It provoked a Government response stating these benefits would be protected. As importantly, it put social care and disability at the forefront of any further Government policy decisions.

Doing this is simple. You



have to tell your story, build your community and make your call to action.

Start with a compelling story. I wanted to talk about disability in an inspirational and progressive way. So I started my blog **martynsibley.com** and began writing about my views. You can also use Facebook, tumblr or myspace as a platform to explain your views and motives. Not only do I write but I show my interesting photos on flickr and upload short video blogs from vimeo (just google these

sites to find them). Then I embed them on my main site. This way my story is more interesting and unique. I also use Twitter and Facebook to update people on real time events allowing supporters to feel a part of what I am campaigning for.

But telling the story is only the beginning. For a while I was adding content but with nobody listening to me. Start by googling disability blogs

and discussion forums. Listen to what others are saying and who seems to have an influence. Then start to participate and air your own views. Use Twitter to follow people with similar views and start two-way conversations. I have met three people through Twitter who I am working on projects with. In time people will engage with you as long as you inspire them in some way. You cannot do it alone and should aim to learn from others as you go.

Then comes the "call to action". For Obama it was asking people to door knock, phone people, give money etc. For the disability e-petition it was as simple as getting people to sign their name to a purpose. The call to action can be small or big.

Just get online, inspire and change something for the better.

→ Have your say

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- email us **editor@disabilitynow.org.uk**
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Mark's business package



No one can say that **Mark Livsey** has failed to deliver. From a start-up grant from the Prince's Trust, he now has a fleet of 20 vehicles and is keeping things moving all over the north-west

Parcel Partners Ltd is a logistics company. So rather than being a same-day delivery firm, we manage our clients' delivery network.

So, if we're approached by someone who supplies goods nationally, we have our own vehicles to deliver in the north-west of England and we'd find the best carrier to outsource the rest.

We deliver about 6,000 packages a week: toilet rolls, engines, ladders, electrical goods – anything except hazardous liquids.

We've got 20 vehicles at the moment and 25 staff. A typical day for me involves administration work,

visiting clients, and dealing with the accounts. I can't do any of the driving: it's impossible. I'm not in a wheelchair but I do need wheelchair access. I've bought all these seven-and-a-half tonne trucks but I can't get into the things. It's frustrating but that's the way it is.

The main reason I set up the business is that I've got a young family and wanted to create a job that would give me a comfortable life. I used to be in the courier business when I was 19 and knew that quite a lot of courier firms sub-contract their routes so I knew there was work there, and the

delivery industry seemed to be sustainable because more people are ordering goods on the internet.

I got a contract but didn't have any money to fulfil it, so I went to the Prince's Trust and they gave me £4,000 to buy a vehicle. Having got 20 I can't get any more investment from the banks to buy any more. But I'm looking for new investment because there are opportunities there and I'm having to turn down new business.

I work from home and I can manage all my drivers from here on the phone, because our vehicles are based at other courier company sites in the north-west.

One reason why we're different from other sub-contractors is that many business owners are also the ones driving the van. I manage from a distance, see what problems the drivers have and react to

them, which I couldn't do if I was delivering.

It's quite a physical industry but people help me when they see me struggling with my cane.

There's only ever been one person who's been negative about my disability. We'd been talking on the phone and we were talking about which vehicles we were going to use, which runs we could do and even start dates. But as soon as he saw me face-to-face, he changed completely and said, "Um, I don't know if we've got any opportunities at the minute." I walked out.

In five years' time, I want to be competing with the likes of Wincanton, which is one of the largest logistics firms in the UK, doing deliveries for the likes of Tesco, Shell and Unilever.

My advice is never give up. If you believe in yourself, your self-belief will win through. It'll be harder because of your disability, but if you get over that fact, you'll be alright.

• **Mark Livsey was talking to Sunil Peck**

MARK LIVSEY: CAREER PATH

- 1994 – Left Prestwich High School. Went to Bury College to study business
- 1999 – Studied for an HND in business at the University of Salford
- 2000 – Went to work in finance in Bangkok
- 2001 – Came back to England to work in recruitment
- 2004 – Set up a mobile phone company
- 2007 – set up Parcel Partners Ltd

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DN DEADLINE - May 2010 published 28 April. Classified deadlines: Booking: 6 April. Copy: 8 April.

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backlash



The doctor dilemma

Even when he's genuinely under the weather, **Paul Carter** wrestles with why he's reluctant to see a doctor

Sorry to report that since I last put drivel to paper, I've been a bit off-colour.

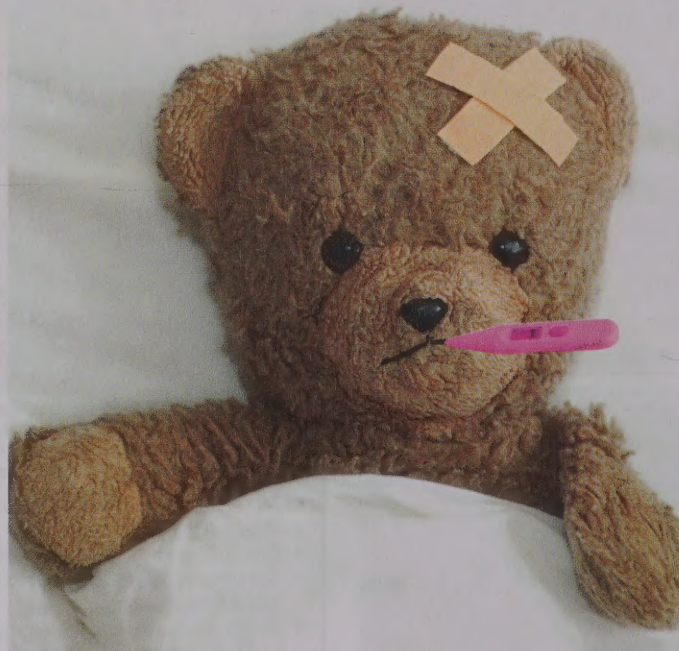
For a while there I was very much stuck in a world of cold sweats, Lucozade, and longing for the times when days off sick meant watching re-runs of *Thundercats*, *Happy Days* and *The Monkees* TV show, rather than pathetically trying to respond to work emails on the Blackberry from under a duvet.

I've been reliably informed by just about everyone since I fought bravely back into work though that "there's something going around, I think".

I've come to the conclusion that there is always something "going around" though isn't there? Whether it's a cough, a cold or the bubonic plague, it's always something.

However ill I get though, I try my hardest not to give in and go to the doctor's, largely because I find it such a massive ballache (not literally, or I would go).

I think many GPs would find being faced with the human incarnation of the



smallpox virus less terrifying than looking up to see little old disabled me skulking through their surgery door.

You can see the panic on their faces, almost like they're expecting me to say "hello doctor, I've woken up this morning and something most awful has happened. I passed glance upon my extremities and could not fail to discover that my arms appear to have fallen off". (I also imagine my conversations with doctors take place in a cod-Victorian dialect. I'm not really sure why.)

“I think many GPs would find being faced with the human incarnation of the smallpox virus less terrifying than looking up to see little old disabled me”

If they don't think you've come about the glaringly obviously incurable, they react as if someone made of the most delicate crystal known to man has just presented. Either that or

they seem convinced that whatever I may have wrong with me, is related to my impairment, as if there's some undiscovered link between vomiting and leglessness. Actually, come to think of it...

However, I do remember one time back when I was a student, I went to the doctor's once only to be told that, in fact, he couldn't do anything for me, as I had a virus.

Now apparently viruses aren't alive or something, I'm not sure I wasn't really listening, so antibiotics or voodoo or whatever it is they use these days wouldn't work. So helpfully, they gave me a leaflet, which spent three pages telling me even more helpfully they couldn't do anything for me. Because I had a virus! That was a worthwhile trip, the leaflet did actually help though. I felt so damned cold by the time I'd done a round trip to the surgery that I set fire to it.

Anyhow, I'm off to look pitifully at strangers in the vain hope of getting some sympathy. Cough cough.

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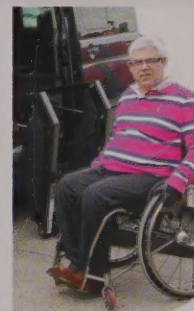
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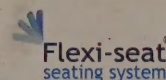
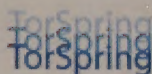
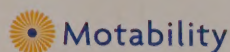
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